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Intersex, Variations of Sex Characteristics, and DSD: The Need for Change

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# **Intersex, Variations of Sex Characteristics, and DSD: The Need For Change**



A Report by Surya Monroe,  
Daniela Crocetti,  
and Tray Yeadon-Lee,  
with Fae Garland and Mitch Travis

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Subjects: S. Temko (foreground); V. Vecchietti (back right); S. Welsh (back left).

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The views presented in this report are those of the research contributors and the report authors. They are not necessarily the views held by the Universities of Huddersfield, Leeds, and Manchester.

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## Key Recommendations

1. A National Review of Disorders of Sex Development (DSD) and Intersex and Variations of Sex Characteristics (IVSC) Policy and Practice is urgently required. This should address the need to properly implement existing guidelines, develop more effective patient<sup>1</sup>-centred care pathways, and improve support for affected families.
2. There is a need for cross-party and policy-maker attention to the research findings. Key organisations could usefully consider the report; these include NHS England, the Care Quality Commission, the General Medical Council, the Royal College of Medicine, the Royal College of Surgeons, the Society for Endocrinology, the British Society for Paediatric and Adolescent Gynaecology, the British Association of Paediatric Urologists, the Royal College of Nursing, the Royal College of Midwives, and the British Psychological Society.
3. A legal moratorium should be put in place to prevent unnecessary surgeries and other irreversible harmful procedures being carried out on infants and children too young to give informed consent. Cosmetic surgical procedures may be required later by some IVSC children and young people who are capable of giving fully informed consent. Legal measures are needed to protect children from harmful interventions that are carried out because of social, not medical, reasons.
4. The area of DSD and IVSC children's wellbeing and protection from harm is neglected by current child protection guidelines. Concerns that some IVSC people and NGOs raise about the alleged abuse, torture, and genital mutilation of DSD and IVSC infants and children require attention.
5. Updating of the Equality Act (2010) and other areas of legislation, including birth registration, is needed. This will remedy the legal deficits that currently exist regarding people who are intersex/have variations of sex characteristics.
6. IVSC people must be properly consulted, included, acknowledged, and remunerated in any policy work and practice interventions that are carried out. This includes situations where 'Intersex' is included together with 'Lesbian, Gay, Bisexual, and Transgender' to form the 'LGBTI' acronym.
7. There is a need to review use of the term 'Disorders of Sex Development' (DSD) to describe people who are intersex/have variations of sex characteristics. The term 'DSD' is pathologising and its reconfiguration into 'Differences of Sex Development' does not distance sufficiently from the pathologisation of the original term. 'IVSC' is an inclusive term that is non-pathologising; it is one of the terms that could be considered.

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<sup>1</sup> The term 'patient' is used here to denote an individual receiving care from healthcare providers, not an individual who has a pathological condition.

## Executive summary

- Medics working in the field are in a difficult position, as they are trying to support children and families with highly invisible conditions. The severe, harmful effects reported as a result of early childhood interventions need to be acknowledged and addressed. Improvements are urgently required regarding care pathways. Support and training for medics - including about sex diversity issues - is needed.
- It is crucial that DSD/IVSC children have access to the treatments that they may require, once they are old enough to make informed decisions. There is a distinction between the life-saving treatments that they may need in infancy/early childhood, and other treatments which can and should be delayed.
- Emotional and practical support for families is essential, and this should include referral to IVSC support groups and NGOs. Improved long term care for DSD/IVSC adults is also important.
- Improved clinical governance in the DSD/IVSC areas is called for, including the development of robust mechanisms for consultation with DSD/IVSC people and their families.
- The social model of IVSC health needs developing - at present, many interventions are taking place for social/cultural reasons rather than the best interests of the child. Society has changed to support greater gender and sexual diversity, and this enables a more diversity-positive approach to DSD/IVSC care to be developed. This may also save the NHS funds that are currently being wasted on unnecessary interventions and aftercare.
- There is a deficit in child protection policies for DSD/IVSC children. At present, parental preferences override those of their children. Parents are subject to social pressures and may be encouraged by clinicians or others to support irreversible medical procedures that are problematic longer term.
- Legal change is called for, including legislation to prevent unnecessary medical interventions being carried out on children too young to give informed consent, and legislation to prevent sex discrimination on the grounds of IVSC.
- Human rights deficits are highly evident in the DSD/IVSC field. The UK is currently out of line with international directives and guidelines. International hard and soft law in this area provides a resource that UK stakeholders can refer to.
- The reproductive rights of DSD/IVSC children are breached when they are sterilised without consent, except when there is a diagnosis of immediate threat to life if sterilisation does not take place.
- Concerns are being raised about the widespread practice of terminating healthy IVSC fetuses. IVSC fetuses are being terminated due to the framing in the Abortion Act 1967 of IVSCs as serious abnormalities.
- IVSC NGOs and support groups are severely under-resourced and overstretched. There is a pressing need for properly resourced capacity-building of the sector and the development of effective mechanisms to enable the full range of IVSC people to contribute to policy making and service improvement across different sectors.
- The inclusion of Intersex alongside LGBT is very problematic, because IVSC people's issues are legally, medically, and socially different from those of LGBT people. If 'I' is to be placed with LGBT then it is necessary to fully include, resource, and acknowledge IVSC people, and to address their specific concerns.
- There is considerable scope for the development of strong policies, implementation mechanisms, and sector-specific guidance to support IVSC people across the UK.



# 1. Introduction

Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. It may be a combination of all three elements. Environmental influences such as endocrine disruptors can also play a role in some intersex differences<sup>2</sup>. The term 'Intersex' refers to people born with a combination of sex characteristics (chromosomal, gonadal and/or anatomical<sup>3</sup>) that do not fit the typical definitions of male or female<sup>4</sup>. There is a lack of total clarity about the number of babies born in the UK with intersex traits<sup>5</sup>. The British charity dsdfamilies estimates that around 130 babies born in this country each year need investigations before their sex is assigned<sup>6</sup>. The United Nations estimates that between 0.05% and 1.7% of infants are born with intersex traits<sup>7</sup>. Some variations of sex characteristics, including hypospadias, are not always considered to be intersex, hence the variation in figures.

This report addresses issues concerning medical interventions, absences in legal protection, and equalities issues affecting UK-based intersex people and those with Variations of Sex Characteristics<sup>8</sup>. This group are currently termed as having 'Disorders of Sex Development' or 'Differences of Sex Development' in medical settings (DSD). Current developments – including increasing calls from intersex people and those with variations of sex characteristics for urgent attention to the UK situation – mean that this report is timely, but also that the situation may be fast-changing.

The terms 'Disorders of Sex Development' was introduced in the Chicago Consensus Statement 2006<sup>9</sup> and subsequently this term, and the term 'Differences of Sex Development' are used in medical settings for people who are intersex and/or have Variations of Sex Characteristics. The report does not refer to these terms except where they are highlighted in the findings. This is because those people personally affected by intersex and Variations of Sex Characteristics who contributed to the research all reject the term 'Disorders of Sex Development'. Appendix 1 addresses the issue of terminology. This report takes a standardised approach, using the term 'Intersex and Variations of Sex Characteristics' (IVSC). However, it is acknowledged that some people prefer other terms, such as 'Variations of Sexual Development', or variation specific terms. One parent contributor, the member of dsdfamilies, prefers the term 'Differences of Sex Development'. Where the term 'patient' is used in the report this is to describe an individual receiving care from healthcare providers, not an individual with a pathological condition.

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<sup>2</sup> Oiiuk.org.

<sup>3</sup> Including hormone receptor variants.

<sup>4</sup> Lee, P. Houk, C., Ahmed, F.S. and Hughes, I.A. (2006). 'Consensus statement on management of intersex disorders'. *Pediatrics*, 118, 488–500, doi: 10.1542/peds.2006-0738

<sup>5</sup> ONS. (2017). *Number of Babies with Intersex Traits*. Retrieved from: <https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/numberofbabieswithintersextraits>

<sup>6</sup> See also reference in footnote 2, above.

<sup>7</sup> HCHR. (n.d.) Fact sheet: Intersex. Retrieved from: [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf)

<sup>8</sup> In England the specialised elements of healthcare for IVSC people are commissioned nationally by NHS England. A service specification for complex congenital gynaecological anomalies has been developed by an advisory Clinical Reference Group and is available on the NHS England website at <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e09/>. Additionally, all health and social care services in England are routinely inspected and regulated by the Care Quality Commission <http://www.cqc.org.uk/>.

<sup>9</sup> Hughes, I.A. et al. (2006). *Consensus statement on management of intersex disorders*. Retrieved from: <http://www.aissg.org/PDFs/Chicago-Consensus-Statement-06.pdf>

IVSC and DSD care is a complex field increasingly addressed by multidisciplinary teams. There are medical professionals in this field who labour to better a patient centred care model that is truly 'focused upon the best possible quality of life (QoL)<sup>10</sup>'. The report acknowledges the fact that medical practitioners may find themselves in difficult decision-making positions regarding early childhood surgery and other interventions, particularly when early interventions are sought by parents. The 2016 update to the 2006 Consensus Convention guidelines states:

'Although parents are responsible for consenting to interventions believed on the basis of available evidence to be in the best interests of their child, their right to consent to non-medically necessary irreversible procedures that may adversely affect the child's future sexual function and/or reproductive capacity has been questioned, particularly when such parental decisions preclude the child's ability to be involved in decision making<sup>11</sup>'.

The 2006 Consensus Convention guidelines were aimed at creating patient centred care focusing on the psychosocial wellbeing of the individual and their family, encouraging psychosocial as opposed to surgical interventions. The 2016 update indicates 'There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low while most are supported by team expertise<sup>12</sup>, and they indicate an agreement amongst experts on delaying vaginal and gonadal surgeries until the individual can participate in decision-making. The update continues to highlight the lack of evidence to support irreversible delay-able surgeries, yet again (as in 2006) indicating that there is a need to create a solid evidence base for practice that includes user opinions and rigorous support group involvement. Therefore, this report intends to encourage the implementation and monitoring of the updated Consensus Convention guidelines (2006/2016) that already encourage fully informed consent and decision making, as well as the postponing of surgeries that can be delayed in the interest of prioritizing sexual and reproductive function. The analysis of research data provided in this report supports the 2016 update query regarding the rights of parents to make decisions for their children that might impair sexual and/or reproductive function. More research is needed that rigorously includes user perspectives.

This report is based on empirical material collected between February and May 2017 in the UK, as part of a project<sup>13</sup> taking place between September 2016 and August 2018. This qualitative project investigates human rights issues, and approaches to Intersex and DSD in Europe (specifically focusing on Italy, Switzerland and the UK). It maps the agendas, actions and results of the diverse Intersex and DSD activists, and aims to include the views of clinicians and policy makers working in the Intersex and DSD area. Eighteen qualitative interviews were conducted in the UK (one NHS healthcare professional, six intersex people, three patient advocates, one member of a family support group, and two representatives of LGBT organisations doing work about intersex, some of whom are also intersex), four civil servants and one union representative. In addition, officials from the Government Equalities Office and the Cabinet Office provided information on intersex inclusion in the UK's Civil Service (see Appendix 4) and written responses were received from the Northern Ireland Office of the Deputy Prime Minister and from a further patient advocacy organisation. More details about the research methods for this project are in Appendix 2.

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<sup>10</sup> As footnote 1, above.

<sup>11</sup> Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., & Mazur, T. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone Research in Paediatrics*, 85(3), 158-180.

<sup>12</sup> As footnote 8, above.

<sup>13</sup> See [https://www.hud.ac.uk/research/researchcentres/criss/projects/intersex-dsd\\_human\\_rights/](https://www.hud.ac.uk/research/researchcentres/criss/projects/intersex-dsd_human_rights/)

This study was limited in a number of ways, due to resource constraints. It is a small qualitative study, lacking data in particular from clinicians. The medics who were invited to contribute to the research were unable to respond; some of them referred the team to published outputs, which have been used in the report. The report includes analysis of NHS data, but this is limited due to the nature of the publically available material as well as the scope of the project. The findings indicate a pressing need for further research concerning DSD, intersex, and variations of sex characteristics in the UK. This should address private as well as NHS healthcare provision. This report provides a means of fostering discussions and it is not intended to be conclusive.

Readers should assume that the report is discussing the material provided by the intersex interviewees and advocacy/support group members, unless specified otherwise. In some places, sections of the quotes from contributors are highlighted in bold to emphasise points. Interviewees were asked about their preferences regarding anonymisation; only two preferred the use of pseudonyms to their real names<sup>14</sup>.

## 2. Medical, Healthcare, and Support Issues

### 2.1 Are Variations of Sex Characteristics and Differences of Sexual Development a problem?

Medical interventions concerning intersex were made routine during the 1950s, for people with bodily characteristics that were previously kept in the private realm and not routinely pathologised<sup>15</sup>, and a wide range of interventions are now put in place regarding variations of sex characteristics<sup>16</sup>. Some of these interventions are life-saving and necessary, for example if a baby is born without the capacity to urinate or if hormone treatment is required (as in the case with variations of Congenital Adrenal Hyperplasia (CAH)). However, many of the interventions currently taking place are not necessary for physical functioning.

*...so many very healthy Intersex children are not allowed to develop without some medical intervention. Also this decision that is made on their behalf, shortly after birth, possibly as soon as just a few weeks old, is that somebody else gets to decide what their gender identity is (Dr Jay Hayes-Light, Director, UK Intersex Association).*

Intersex NGOs and the patient advocacy groups in the UK are attempting to reframe intersex diversities as part of the natural variation of human bodies, as opposed to being medical problems requiring intervention in themselves. This includes representatives of specialist groups and NGOs such as Intersex UK and AISSG UK<sup>17</sup>. This research shows that the labelling of IVSC as 'abnormal' and 'disordered' by the medical profession has negative impacts on the lives of the people who have these characteristics:

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<sup>14</sup> The pseudonyms are: Ellie, Founder member of dsdfamilies and Annie MacDonald, representative of Trans Media Watch.

<sup>15</sup> Fausto-Sterling, A. (2000). *Sexing the Body*. NY: Basic Books; Caffaratto, M.T. (1963) *L'ermafroditismo umano*, Saluzzo: Minerva Medica; Foucault, M. (1980). *Herculim Barbin*, NY: Pantheon books; Dreger, A.D. (1998). *Hermaphrodites and the Medical Invention of Sex*. Cambridge, MA: Harvard University Press; Reis, E. (2009). *Bodies in Doubt: An American History of Intersex*, Baltimore: John Hopkins University Press; Karkazis, K. (2008) *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke: Durham.

<sup>16</sup> Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A.;... & Mazur, T. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone Research in Paediatrics*, 85(3), 158-180.

<sup>17</sup> Androgen Insensitivity Syndrome Support Group (AISSG). (n.d.). Retrieved from: <http://www.aissg.org/>

*... The notion that our sex development is disordered undermines notions of legitimacy of our sexual identity, of our sexualities, as well. It undermines many levels of what it might mean to be a person (Valentino Vecchiotti, Intersex rights activist, independent academic, and author).*

It is recognised that medical diagnosis can enable access to healthcare. Intersex people and those with variations of sex characteristics may need access to specialist healthcare. This is the case when medical interventions are necessary for survival, where they are felt to be needed by children who are mature enough to make fully informed choices, or by adults with variations of sex characteristics who feel that they need medical interventions. However, this is not the same as framing an entire group of people as having a problem or suffering from pathological conditions. Some contributors were positive regarding the NHS overall, but expressed concerns about the approach of some medics:

*With the greatest respect to many, many, many members of the medical profession that I know who are wonderful and go out of their way to help us, but there's still far too many medical practitioners who either regard it as something that has to be treated and treated medically, or they don't know very much at all (Dr Jay Hayes-Light, Director, UK Intersex Association).*

The framing of IVSC as pathological clearly underpins much of the treatment protocol and practice currently taking place in the UK. In best practice statements and inter-disciplinary reports, medical specialists in this field indicate their awareness that early childhood surgery is the most contentious aspect of their practice<sup>18</sup>. Practitioners working with adults, and paediatricians, often display different perspectives regarding timing of surgery and therefore opinions on consent, bodily integrity and autonomy for children. Some practitioners in adult care have questioned the undiminished rate of surgical procedures in early childhood<sup>19</sup>, and the lack of protocols to encourage non-surgical pathways for parent decision-making<sup>20</sup>. A recent landmark study in France is the first to study the psychological health of children and families with genital differences that do not opt for surgery, indicating highly positive results<sup>21</sup>.

## **2.2 The Social Model of Intersex and Variations of Sex Characteristics**

The research findings indicate that 'problems' regarding IVSC are primarily located in wider society, where rigid ideas about male and female bodies are common. Some of the medics and others working in the IVSC area state that 'we share the concerns of intersex activists regarding the discomfort of society towards gender [sic] variances'<sup>22</sup>. On a socio-cultural level,

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<sup>18</sup> As footnote 9, above; Ahmed, S. F., Achermann, J. C., Arlt, W., Balen, A., Conway, G., Edwards, Z. & Miles, H. (2016). Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015). *Clinical Endocrinology*, 84(5), 771-788; Mouriquand, P., Caldamone, A., Malone, P., Frank, J. D., & Hoebeke, P. (2014). The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD). *Journal of pediatric urology*, 10(1), 8-10.

<sup>19</sup> Creighton, S. M., Michala, L., Mushtaq, I., & Yaron, M. (2014). Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same? *Psychology & Sexuality*, Vol. 5 (1), 34-43.

<sup>20</sup> Liao, L. M., Wood, D., & Creighton, S. M. (2015). 'Parental choice on normalising cosmetic genital surgery'. *BMJ*. Retrieved from: [http://aisdsd.org/wp-content/uploads/2015/10/Liao-creighton-2015-bmj.h5124.full\\_.pdf](http://aisdsd.org/wp-content/uploads/2015/10/Liao-creighton-2015-bmj.h5124.full_.pdf)

<sup>21</sup> Bournèdes, P., Bouvattier, C., Cartigny, M., & Michala, L. (2017). Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. *International Journal of Pediatric Endocrinology*, 2017, 3. Retrieved from: <http://doi.org/10.1186/s13633-016-0040-8>

<sup>22</sup> Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahmed, F., D'Alborton, F., Springer, A., & Hiort, O. (2016). 'Response of the Council of Europe Human Rights Commissioner's Issue Paper on Human

there is widespread ignorance and discomfort about sex variance. The idea that being 'a boy' entails having a penis and testicles and that being 'a girl' entails having a vulva and vagina are still ubiquitous. However, as the healthcare professional who contributed to the study argued, it is not necessary to have a vagina to be a girl, and girls can have penises. If there is more social acceptance of different types of bodies, then there is no need for IVSC to be seen as a problem per se.

*...people are saying this [medical intervention] is necessary because of the way people suffer when they're growing up, emotionally and so on. I think we need to look at the evidence and I don't think that the evidence really does support that assumption. I also think that it tends to be based very much on an assumption that society will remain exactly the same all the time and that there is no room for social change. You know, you could say well some people's bodies are different. I've found from work on Intersex and Trans issues, that when things come up in schools, for instance, and a child is different, in whatever way, often its parents will panic and sometimes teachers will panic, but kids will just take it in their stride and until they encounter prejudice from adults, they tend to continue just being fine with it, because everything is new at that age, there are lots of strange things in the world and it's just another thing, it's no big deal (Annie MacDonald, representative of Trans Media Watch).*

A few research contributors pointed out that in the UK, transgender and non-binary people (those who identify as neither male nor female, both male and female, or in other ways that are not traditionally male or female) are increasingly accepted. People with IVSC usually identify as either male or female. Many of their issues are different from those of trans and non-binary people. Some contributors suggest that some intersex people can also be trans or non-binary, whilst another states that intersex is a different, overarching category, and that *'Intersex children will differentiate their genders, as non-intersex people will'*<sup>23</sup>.

Overall, the increased social acceptance of diversity more widely supports an understanding that IVSC is a part of natural human diversity. A social model of IVSC is now plausible for policy makers, professionals and service providers. A social model of IVSC can be developed based on the lived experiences of intersex people and those with variations of sex characteristics, for example:

*...we're very much a two box society. We have male and female and that is as far as a lot of people, you know, consider, in terms of sex and gender. Whereas actually, **in reality, people's sex and gender is very much a spectrum**. In terms of Intersex, you know, it's a spectrum that goes from male to female, but there's a lot in between and most Intersex people will define as male or female and you know, if they've grown up naturally and then identify as either male or female, then at least they've had a choice to grow into their own identity. But the issue is very much that its forced upon them, you know. Myself, I was born physically male, I've grown to have very much a male gender, however from the age of one, I was forced to be female and grow up female and try and, you know, adopt a female gender. It didn't work and it led to years of issues, because that was taken out of my hands, you know, and it's very much down to society's view of, you know, sex and gender (Dr Jay Hayes-Light, Director, UK Intersex Association).*

*'There are two boxes and that's it'. The reality is that there's a lot more than that (Joe Holliday, Intersex UK).*

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Rights and intersex People', *European Urology*, 70(3): 407-409. Retrieved from: <http://www.sciencedirect.com/science/article/pii/S0302283816301798>

<sup>23</sup> Holly Greenberry, personal communication 12.06.2017.

Overall, the development of appropriate, accessible healthcare is complementary to social model-oriented approaches, as the key issue is the individual IVCS person's choice and control.

*Intersex people, the same as Trans people, should have access to those surgeries if that's what they feel that they need for their bodies, because **it's their body, they should have the right to decide*** (Alex Gardner, Scottish Equality Network).

The research findings indicate that IVCS people need support accessing the care that *they* feel they need, including surgical procedures, hormone treatment, and emotional support. In some cases, earlier and better treatment is called for. For example, early diagnosis of XXY concerns the protection of fertility and access to information (see section 4.2). The issues here are of informed consent, and of people being able to decide for themselves what interventions they need, based on the best available information and healthcare provision.

### 2.3 Early Medical Interventions

Overall, contributors are extremely worried about the impacts of early medical interventions where these are not necessary for basic physical wellbeing. The outcomes of surgical procedures and medication on babies and children with IVSC are typically reported as being poor and/or damaging<sup>24</sup>. Medical practitioners indicate there is very little follow-up research on the long-term satisfaction of IVSC people following medical interventions<sup>25</sup>.

*...medically altered, either via surgeries, medication, all sorts of different treatments, which are altering the body of the child, when they don't fully understand what's happening to themselves, and then it can be a **devastating long lasting effect on the child, and yeah completely ruining their lives in some cases**...it's all hugely experimental and that's, very very damaging then, it has long term effects...they might operate on someone's genitals just because something doesn't look quite right, but that person's going to be **in and out of hospital for the rest of their life*** (Dawn Vago, Intersex UK).

*A child is going to want, one day will grow up into being a young person and will be no different in so many regards to the people who are reading this...you only have to imagine as the reader right now, what it's like for genitals to have been removed, or your gonads to have been removed and the other harm is the silent harm, the typically, typical symptomatic damage of removing your gonads, for the rest of your life. I mean*

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<sup>24</sup> Creighton, S. M., Minto, C. L., & Steele, S. J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *The Lancet*, 358 (9276), 124-125.; Minto, C. L., Liao, L. M., Woodhouse, C. R., Ransley, P. G., & Creighton, S. M. (2003). The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study. *The Lancet*, 361 (9365), 1252-1257.; Crouch, N. S., Liao, L. M., Woodhouse, C. R., Conway, G. S., & Creighton, S. M. (2008). Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia. *The Journal of urology*, 179(2), 634-638.; Canning, D. A. (2015). Can We Correct Hypospadias with a Staged Operation? If not, are We Bold Enough to Report it?. *The Journal of urology*, 194(2), 284-285.; Lorenzo, A. J., Salle, J. L. P., Zlateska, B., Koyle, M. A., Bägli, D. J., & Braga, L. H. (2014). Decisional regret after distal hypospadias repair: single institution prospective analysis of factors associated with subsequent parental remorse or distress. *The Journal of urology*, 191(5), 1558-1563.; Diamond, M., & Garland, J. (2014). Evidence regarding cosmetic and medically unnecessary surgery on infants. *Journal of Pediatric Urology*, 10(1), 2-6.

<sup>25</sup> DiSandro, M., Merke, D. P., & Rink, R. C. (2015). Review of current surgical techniques and medical management considerations in the treatment of pediatric patients with disorders of sex development. *Hormone and Metabolic Research*, 47(05), 321-328.

*the inability, the clarity, the brain fog, the memory loss, the damage to libido, **the damage to your right to pleasurable sexual encounters** with your chosen partner. I mean, you know, and what the shame and stigma does...*(Holly Greenberry, Intersex UK).

Early irreversible interventions are also problematic because some IVSC children and young people's bodies change as they grow up, in a different way to that associated with the sex they were assigned to. They may decide that their sense of personal gender identity is other than that to which they were assigned as a baby. For instance, one contributor noted that five to ten per cent of children with congenital adrenal hyperplasia (CAH) define themselves as male when they are older, but surgical vaginal constructions and dilations are reported to be taking place on babies and children under the age of two.

The literature provides substantial evidence for the damaging effects of surgical procedures on IVSC children. Clitoral reduction and/or clitoroplasty can greatly reduce or eliminate sexual sensation in the future adult, and can contribute to sexual difficulties<sup>26</sup>. Other plastic genital surgery can also greatly reduce or eliminate sexual sensation, or contribute to sexual problems in the future adult. Iain Morland, among others, claims that early childhood cosmetic surgical procedures do not provide the child with a 'normal' body and healthy self-esteem, but rather a surgically marked and scarred body. Convincing that their body was 'wrong' and needed to be 'fixed' can lead to difficulties with physical intimacy as an adult<sup>27</sup>. A recently published report on the UK situation details numerous problems with historically conducted childhood surgical procedures. Testimonies were gathered from 10 British individuals with a range of conditions, all of whom described very poor physical and psychological outcomes (see pages 19-24)<sup>28</sup>. Problems are documented concerning a range of interventions. For instance hypospadias surgical procedures have a high complication rate, often necessitating repeat procedures and causing life-long urinary tract infections or repeat fistulas<sup>29</sup>. Vaginoplasty requires manual maintenance in the form of penetrative dilation by either a physician or parent, and can require additional 'corrective' interventions.

More broadly, according to the World Health Organisation<sup>30</sup>, sexual expression is a healthcare issue and people's access to sexuality and sexual expression should be supported. Sexual expression is a domain in the International Classification of Functioning, Disability and Health where it is framed as an Activity of Daily Living. Sexuality is recognised as being important for

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<sup>26</sup> Minto, C. L., Liao, L. M., Woodhouse, C. R., Ransley, P. G., & Creighton, S. M. (2003). 'The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study'. *Lancet*, 361(9365):1252-7; Lean, W. L., Hutson, J. M., Deshpande, A. V., & Grover, S. (2007). Clitoroplasty: past, present and future. *Pediatr Surg Int*, 23: 289–293.

<sup>27</sup> Morland, I. (2009). What can queer theory do for intersex?. *GLQ: A Journal of Lesbian and Gay Studies*, 15(2), 285-312.

<sup>28</sup> StopIGM.org; Zwischengeschlecht.org, Bauer Markus, Truffer Daniela, IntersexUK, Holly Greenberry, Dawn Vago, OII-UK, Leslie Jaye, UKIA, Dr J. Hayes-Light, (2016). Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC) (2016). Retrieved from: [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf) (see pages 9-12)

<sup>29</sup> Springer, A. (2014). Assessment of Outcome in Hypospadias Surgery – A Review. *Frontiers in Pediatrics*, 2.; Lorenzo, A. J., Salle, J. L. P., Zlateska, B., Koyle, M. A., Bağli, D. J., & Braga, L. H. (2014). Decisional regret after distal hypospadias repair: single institution prospective analysis of factors associated with subsequent parental remorse or distress. *The Journal of urology*, 191(5), 1558-1563.

<sup>30</sup> WHO (2001). *International Classification of Functioning, Disability and Health (ICF)*. Retrieved from: <http://www.who.int/classifications/icf/en/>



people's wellbeing<sup>31</sup>. However, it appears that the future sexuality of IVSC infants and children is being overlooked by current practices. Due to the significant and irreversible nature of the repercussions of these medical interventions, there is a need to reconsider what the best interests of the child are - the idea that normalising interventions are really best for a child is highly problematic.

## 2.4 Issues of informed consent

The IVSC people contributing to this research want consent to lie with the intersex child/young person, not the parents. They want medics to wait before conducting interventions (unless they are necessary for life and basic physical wellbeing) until the child is old enough to contribute to care plans meaningfully. A few discussed the Gillick Age of Competency<sup>32 33</sup> as a useful guide. Under Gillick Competency, children have been able to consent to treatment, but it is unclear whether it has ever been used to enable children to refuse treatment. Some contributors outline a broader need for healthcare practitioners to help children and young people develop their sense of bodily autonomy, which can help them make decisions that are right for them:

*I think it's also very important that from very young, children are made aware that it is their body and so they need to engage with the care of their body and it's even more important to get that across to parents and to the doctors who care for them. So you help to articulate questions and put that in practice: , 'think about your questions, you can ask them to the doctor' and the first few times, that's really quite difficult for a child to do. By reading and talking about it, by sharing information with them, it gets them used to the idea that, yeah, it is their body (Ellie, Founder member of dsdfamilies speaking in private capacity).*

Some of the contributors also emphasise the importance of informed consent for older children and young people choosing whether to have surgical interventions, and the crucial role that psychological support can play in enabling them and their parents/carers to make the right choices for them. Informed consent will of course be important for adults who find out that they have IVSC, for instance when infertility is discovered. Peer support, as provided by IVSC NGOs and advocacy groups, is also seen as crucial for IVSC people and their families<sup>34</sup>.

## 2.5 Unnecessary surgical procedures are still taking place

The 2006 Consensus Statement Guidelines<sup>35</sup> recommends postponing surgical procedures until children are older, and medical best practice statements support postponing such procedures until the individual can be involved in the decision making process<sup>36</sup>. In Scotland, there are reports from stakeholders that unnecessary surgical procedures on babies and young children have ceased, but these have not been verified and may be inaccurate. Overall, frustration with the slow implementation of the 2006 Consensus Statement Guidelines is

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<sup>31</sup> Couldrick, L. (1998). Sexual Issues within Occupational Therapy, Part 1: Attitudes and Practice. *British Journal of Occupational therapy*. 61 (12), 538-544. doi: 10.1177/030802269806101201.

<sup>32</sup> NSPCC (2017). A Child's Legal Rights – Gillick Competency and Fraser Guideline. Retrieved from: <https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines/> (accessed 9.5.17)

<sup>33</sup> The Gillick case only applies to England and Wales. Scotland has similar provisions.

<sup>34</sup> Holly Greenberry, personal communication 12.06.2017.

<sup>35</sup> Hughes, I. A. et al. (2006). *Consensus statement on management of intersex disorders*. Retrieved from: <http://www.aissg.org/PDFs/Chicago-Consensus-Statement-06.pdf>

<sup>36</sup> Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A.;... & Mazur, T. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone Research in Paediatrics*, 85(3), 158-180.



evident in the medical literature<sup>37</sup>. Some impetus to modify IVSC infant and children's care pathways in directions that are non-surgical and/or minimally invasive was reported. For example the healthcare professional reported that:

*... girls have their gonads, until they make the decision not to and they would be fully counselled as to, you know, the pros and cons of keeping them and I would be very interested in them not making a quick decision in terms of those ones that find out about their diagnosis in teenage years. If there's a kneejerk get them out, I would be like no, no, you know, there has to be a process and a sense that that's an informed and a decision made, not in the immediate aftermath of the diagnosis and the adjustment to that. So yeah, I would say our standard practice is that they, girls keep their gonads, but there may be reasons why they're removed.*

However, in actual practice, in the UK overall, IVSC surgical procedures are still being performed on infants and children<sup>38</sup>. Findings from the IVCS research participants indicate that operations are continuing to take place:

*We receive fairly regularly, phone calls from parents and young people who have been subject to, or about to be subject to, significant irreversible medical damage and if the Consensus Statement had worked as it was intended to, then this wouldn't be happening...* (Holly Greenberry, Intersex UK).

Existing, published analysis of NHS data shows that IVSC surgical procedures are still being performed on infants and children, but it is unclear as to the ages when procedures were performed and whether informed consent was gained<sup>39</sup>.

- Over 450 0-14 year olds had testes removed in 2014-2015<sup>40</sup>.
- Numbers of cases where 'atypical gonadal tissue' was removed from 0-14 year olds actually increased in 2014-2015.
- Masculinising genital surgical procedures that are unnecessary for basic functioning are routinely advocated and performed in NHS hospitals for hypospadias, for social rather than medical reasons.
- Surgeons continue to practise clitorectomies which are entirely unnecessary for medical reasons.

Some primary analysis of NHS data was conducted as part of this research project. The data we present is based on the lower primary procedure numbers. The analysis was based on figures for procedures that aggregate data from 0-14 year olds, making it impossible to

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<sup>37</sup> Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahmed, S. F., D'Alberton, F., ... & Hiort, O. (2016). Response to the Council of Europe Human Rights Commissioner's issue paper on human rights and intersex people. Retrieved from: <http://www.sciencedirect.com/science/article/pii/S0302283816301798>

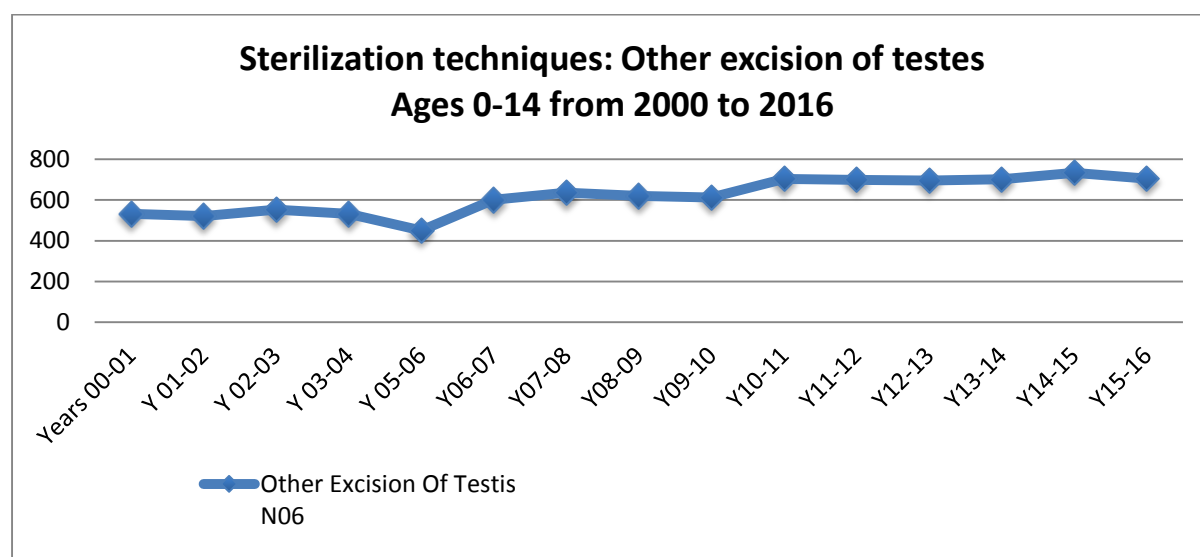
<sup>38</sup> StopIGM.org; Zwischengeschlecht.org, Bauer Markus, Truffer Daniela, IntersexUK, Holly Greenberry, Dawn Vago, OII-UK, Leslie Jaye, UKIA, Dr J. Hayes-Light, (2016). Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC), [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf) (see pages 9-12, last accessed 24/05/17).

<sup>39</sup> StopIGM.org; Zwischengeschlecht.org, Bauer Markus, Truffer Daniela, IntersexUK, Holly Greenberry, Dawn Vago, OII-UK, Leslie Jaye, UKIA, Dr J. Hayes-Light, (2016). Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC) (2016). Retrieved from: [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf) (see pages 9-12)

<sup>40</sup> Numbers may also include necessary treatments of non-intersex children.

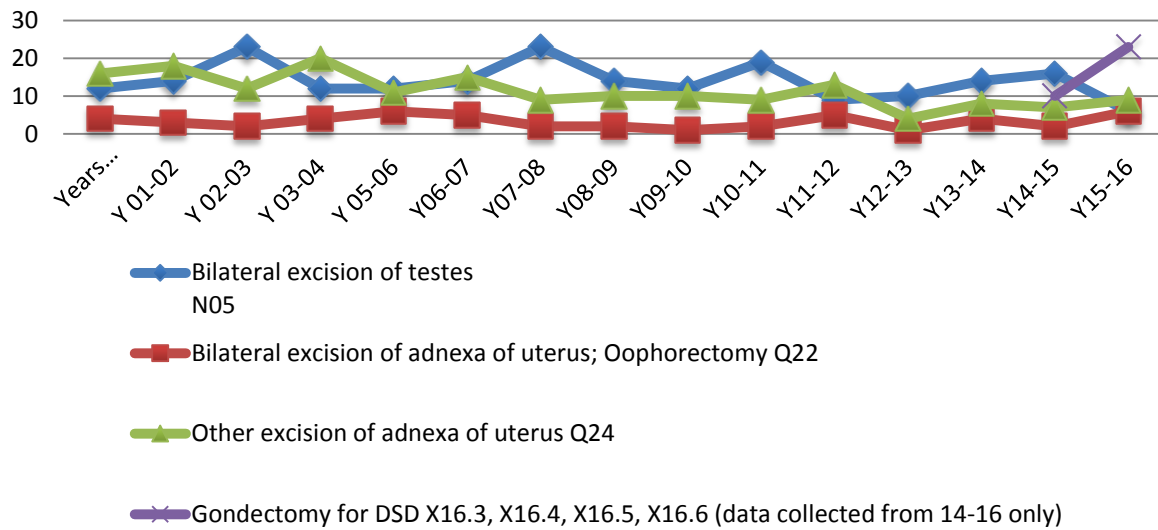
ascertain whether each individual procedure took place at an age where a child was able to give consent. Also, some of the procedures are likely to be treatment for conditions such as penile cancer. Therefore, the analysis provided in the following tables is indicative rather than conclusive. We strongly recommend that a full review of practice be conducted, which disaggregates ages, procedures, reasons for the procedures, and levels of consent provided by the patient. A full review is also required because there are indications that there are often large increases between the numbers reported for primary procedures and for all procedures. This could indicate that these surgeries are not initially 'successful', and have to be repeated more than once, subjecting children to repeat traumatic experiences.

The following charts indicate the continuation of sterilisation, and 'feminising' and 'masculinising' cosmetic surgical procedures in the UK on individuals between the ages of 0 and 14 from 2000 to 2016. These charts *may* indicate little significant change in these surgical practices, including those carried out in infants and very young children, although as noted above the lack of age breakdown of the figures in the publically available NHS data means that it is impossible to make definitive statements<sup>41</sup>.

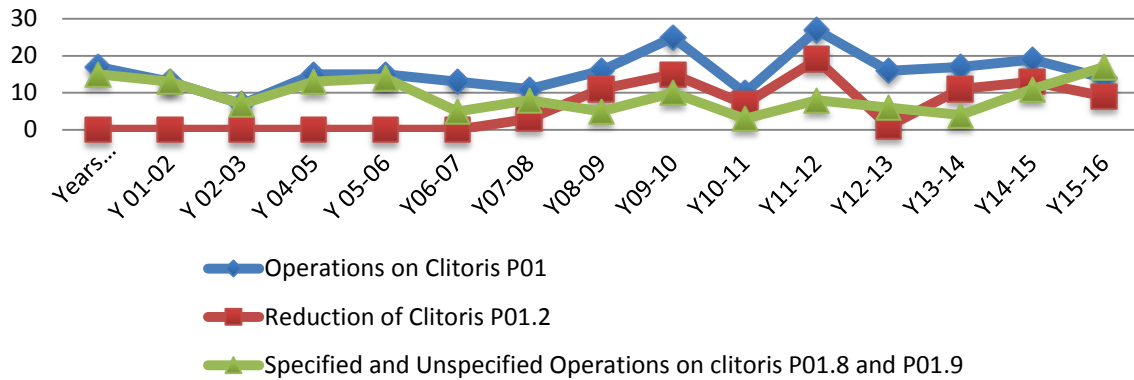


<sup>41</sup> <http://content.digital.nhs.uk/article/2021/Website-Search?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+-+England%22+or+title%3A%22Hospital+Admitted+Patient+Care+Activity%22&go=Go&area=both>  
For the years 2012-2016 NHS-UK YEAR hosp-epis-stat-admi-proc-2015-16 Available from:  
<http://content.digital.nhs.uk/article/2021/Website-Search?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+-+England%22+or+title%3A%22Hospital+Admitted+Patient+Care+Activity%22&go=Go&area=both>  
NHS-UK YEAR hosp-epis-stat-admi-main-ops-4cha-11-12 Available from:  
<http://content.digital.nhs.uk/article/2021/Website-Search?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+-+England%22+or+title%3A%22Hospital+Admitted+Patient+Care+Activity%22&go=Go&area=both>  
For years 2000-2012  
NHS-UK YEAR hosp-epis-stat-admi-main-ops-3cha-11-12 Available from:  
<http://content.digital.nhs.uk/article/2021/Website-Search?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+-+England%22+or+title%3A%22Hospital+Admitted+Patient+Care+Activity%22&go=Go&area=both>

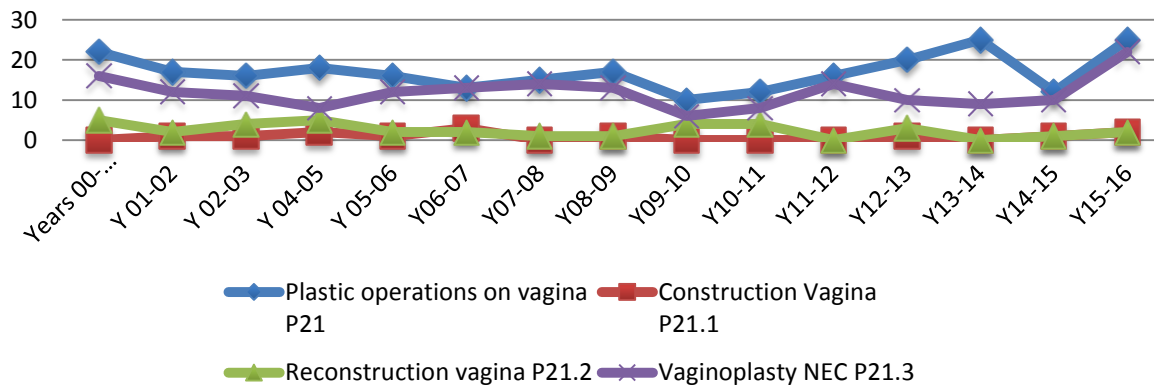
# **Sterilization techniques: Gonadectomy; Bilateral excision of testes; Oophorectomy** **Ages 0-14 from 2000 to 2016**



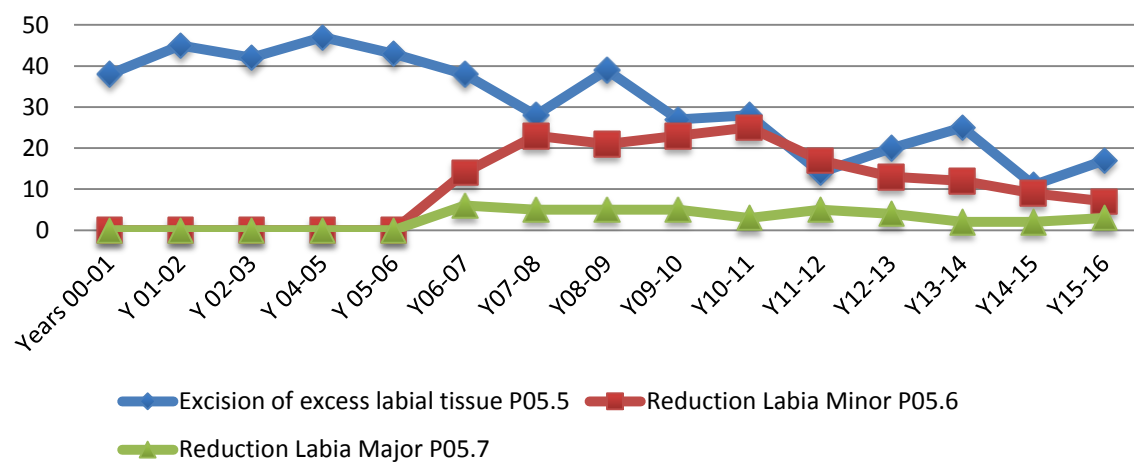
### "Feminizing" surgical procedures: Operations on Clitoris Ages 0-14 from 2000 to 2016

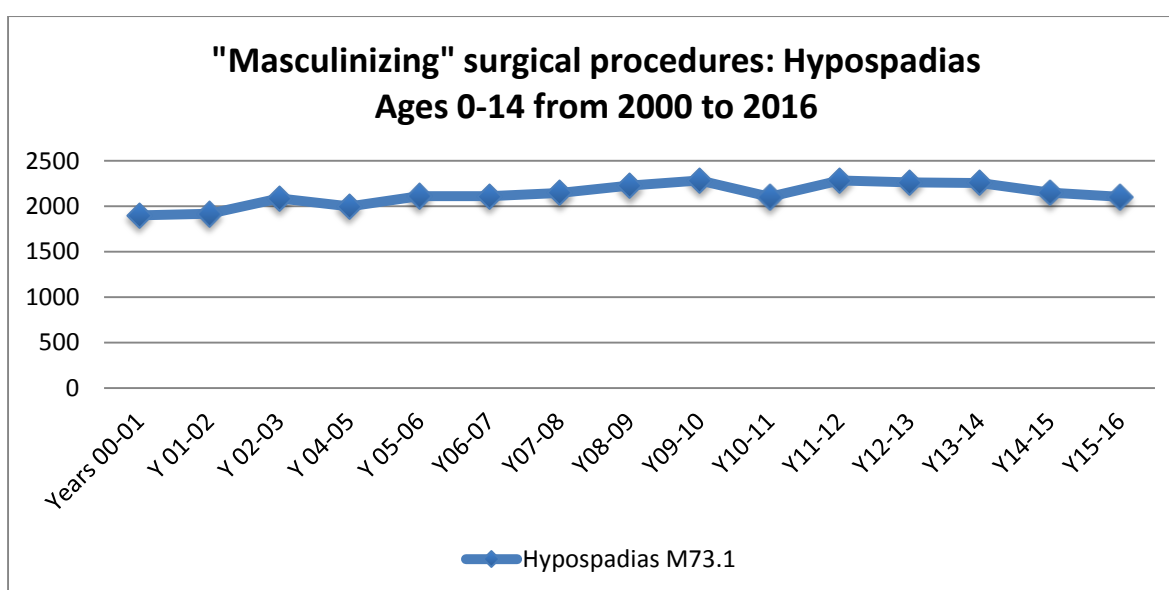
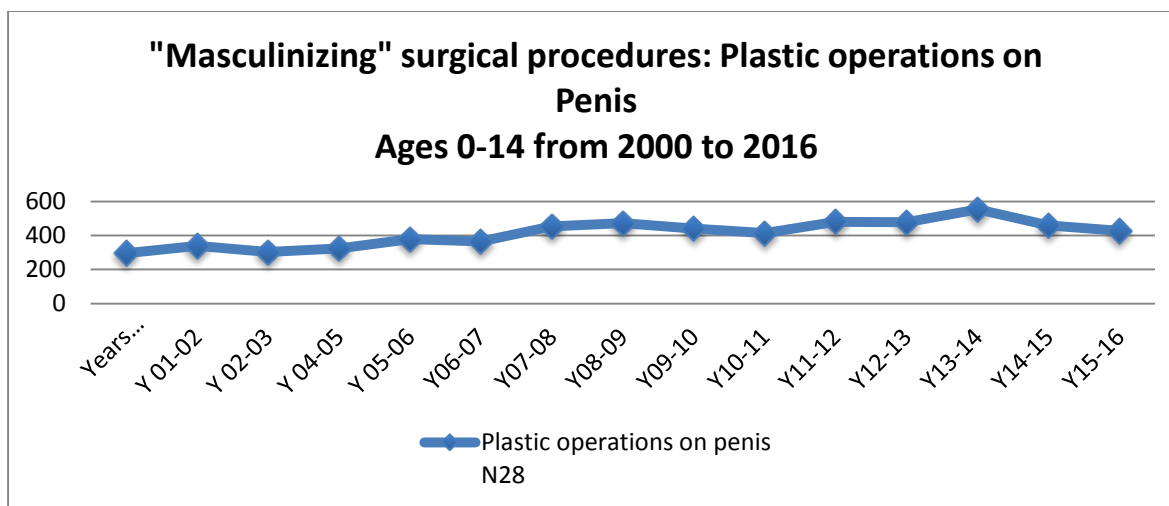


### "Feminizing" surgical procedures: Vaginoplasty Ages 0-14 from 2000 to 2016



### "Feminizing" surgical procedures: Operations on Labia Ages 0-14 from 2000 to 2016





These findings may indicate an implementation deficit regarding the 2006 Consensus Statement Guidelines, which is a matter of pressing concern, given the evidence that early childhood surgical procedures can be harmful and that poor prognosis is common.

## 2.6 What do intersex people and those with Variations of Sex Characteristics think about unnecessary surgical procedures?

IVSC contributors unanimously oppose the practice of surgical procedures on babies and young children, except in cases where these are necessary for basic physical functioning such as urination. Some of the side effects of early surgical procedures can be devastating, including a loss of sexual functioning including ability to orgasm, incontinence, fistulae, and chronic pain.

*Many people, if you were born Intersex, have, you know, a similar experience of having surgeries performed on them, be it cosmetic genital surgery, be it sterilisation, you know, the removal of your reproductive organs and it's all just, well its wrong and for me, you know, I was, you know, sterilised when I was a baby, obviously without my consent and that's something that really, its personal to me and many people who are Intersex, because its, it's just such a, it's a horrible thing to have to experience and live with throughout your life. In terms of the cosmetic surgeries that are performed on*

*Intersex people, it leads to lifelong issues that generally speaking could be avoided, just through actually allowing people who are born Intersex to develop like they should be, naturally... (Joe Holliday, Intersex UK).*

Operations are being performed because of narrow beliefs of doctors and/or parents about how genitals should appear and function, rather than the longer term wellbeing of patients. For example, a doctor might operate on a hypospadias because he thinks that a boy will be bullied or not feel masculine if he has to sit down to urinate. However, hypospadias operations often lead to repetitive medical interventions, lifelong discomfort, trauma, and an inability to have or to enjoy sex (see section 2.3).

Parents seem to be lacking access to the full range of information about the impact of surgical procedures on intersex babies and children. According to one contributor, this information is not made available to them<sup>42</sup>. The complex implications of interventions may not always be spelled out. The healthcare professional reported that colleagues did not always refer parents to patient advocacy groups and intersex NGOs to help them gain information. This contributor also reported that some surgeons are reluctant to discuss issues of future sexual functioning with parents. The member of dsdfamilies who contributed to the research stated that one of the problems is that the non-surgical pathway is simply not articulated.

## **2.7 Why are medically unnecessary surgical procedures for Intersex and Variations of Sex Characteristics taking place?**

More research is needed in order to ascertain the reasons for unnecessary interventions taking place. Indicative evidence is that the reasons for unnecessary early surgical procedures stem from the beliefs and values amongst some medics and parents that non-standard genitalia are a problem that need to be 'fixed' by non-reversible interventions. Early surgical interventions take place in order to make parents and medics feel more comfortable, and/or because of beliefs that a child's life will be more difficult if they have differing genitalia than if they have medical interventions.

*...the medical profession, they tend to advocate that early surgeries are better because 1) it gets it out of the way with and 2) that young children tend to adjust better, heal better, that sort of thing. But you know, the truth is that's not really true. The problem also is, you know, you're taking away a person's right to consent to a procedure because at that age, they can't consent... I'm not saying that, you know, no surgeries should be committed. It's a case of only the very necessary procedures, you know, to bring functions back to save life, is you know, of course, it's something that's needed. It's the unnecessary side of it, cosmetic surgeries, you know, such as, you know, building, you know, performing surgeries on children to give them vaginas, for instance. 1) it's not necessary and 2) it tends not to work and causes issues later on in life because of scarring and tissue growth at different rates and issues like that. Its, it doesn't really make a lot of sense that we would perform those sorts of surgeries on a child... (Joe Holliday, Intersex UK).*

*... if there's surgery available, why would you not do it? Why would you not, why would you not choose to do that for your child? So there's the sense that it is available and it is the right thing to do. The same as pinning the ears back, or closing the cleft, or lengthening the legs, or any of these treatments, we could go 'oh you wouldn't think twice about any elective surgery' (Healthcare professional, NHS).*

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<sup>42</sup> Holly Greenberry, Intersex UK, personal communication 12.06.2017.

The problem is that early surgical procedures on children's genitalia can have devastating side effects, in contrast to, for example, ear pinning<sup>43</sup>. Also, genital surgical procedures are connected to a forcible shaping of a person's gender and sexual possibilities later on, in a way that none of the interventions mentioned in the above quote do. Genital surgical procedures, as 'written' on or in the body, have big implications for the ICVS patient – but attempting to 'fix' diversity via surgery does not necessarily work.

*...they [clinicians] need to know that changing the physical body does not create an identity: a gender identity - and they need to know that presenting that notion to parents is false and it is not, that model, that notion needs to stop, and I think that's kind of at the core of it, that fallacious idea. We have trans people existing now, who clearly show us that their physicality, the way their bodies are shaped, doesn't at all reflect their gender identities...it's very unscientific, **why you'd base surgical models and medical practice on social constructs, it's very unscientific** (Valentino Vecchietti, Intersex rights activist, independent academic, and author).*

Some contributors pointed out that early interventions such as the creation of vaginas via surgery and/or dilation is done in order to enable patients to have heterosexual sex later, which makes assumptions about both the future sexual orientation of an individual and the types of sexual intercourse that are considered 'normal'. Whilst most IVSC children may go on to identify as heterosexual, medical interventions motivated by heterosexist norms are highly problematic. All the contributors support measures to allow people to have genital diversity.

There may be other reasons why surgical procedures are carried out on children before they are able to give consent. One contributor suggests that:

*One of the very important things to change with medical treatment is that it can't be argued anymore that if surgeons stop doing these types of genital surgeries on infants and children, they'll get out of practice, or lose the skills, so they have to keep doing it to maintain their skills. That cannot be used as an argument to perpetuate unnecessary surgeries. It doesn't make sense. It's like saying, 'I need to keep amputating people's feet, I don't want to stop doing it in case I lose the ability to needlessly amputate people's feet, so I must keep doing it.' It's nonsensical. There's no logic to it, there's no meaning to it. That's got to stop, and it's being used to legitimise their argument, and it has somehow persuaded people (Valentino Vecchietti, Intersex rights activist, independent academic, and author).*

There are additional reasons why early medically unnecessary surgical procedures are conducted. These include the high levels of pressure on medics to 'fix' a child (see above), a perceived lack of expertise amongst surgeons in carrying out surgical procedures on older children, including teenagers<sup>44</sup>, and the effects of gender norms<sup>45</sup>.

## 2.8 Hormones

The use of hormone therapy by medics is also questioned by some contributors. It is seen as experimental, given the way that IVSC children's physiological sex characteristics can change over time and the fact that their choice of gender identity cannot be certain when they are very young. For example a representative of a Klinefelter's organisation pointed out that parents

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<sup>43</sup> For a discussion about cosmetic surgical procedures for children see Parens E, (ed) (2006) *Surgically shaping children: technology, ethics and the pursuit of normality*. Baltimore: Johns Hopkins University Press.

<sup>44</sup> Kleeman (2016). 'We don't know if your baby's a boy or a girl': growing up intersex'. Retrieved from: <https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex>

<sup>45</sup> Holly Greenberry, personal communication 12.06.2017.

need to be careful because not all young people with Klinefelter's want to be more masculine. They point out that testosterone hormone treatment can be very helpful for some people, while others have problems including negative side effects, and they hope that there will be more health research in this area. As noted above, some IVSC people need to have exogenous hormones to remedy deficits in their congenital endocrinological makeup. However, the research also raised the problem of medically induced exogenous hormone dependency, when IVSC children and young people's gonads are removed, forcing them into a life of exogenous hormone dependency and the negative health effects that this can lead to. Some evidence exists that older people with IVSC experience deficits in healthcare, for example when hormone dosages are not reviewed for long periods of time, potentially leading to serious health problems<sup>46</sup>. This study indicates a need for more research into the hormonal care issues of older IVSC people.

## 2.9 Vaginal Dilation

The 2006 Consensus Statement clearly states 'Vaginal dilatation should not be undertaken before puberty.' In practice, because vaginal dilation can be required as a follow-up 'maintenance' technique after vaginoplasty, it may be performed before puberty if a vaginoplasty is performed before puberty. Some of the contributors, notably Holly Greenberry from Intersex UK, are highly critical of dilation when performed non-consensually on children; she describes it as a form of medical rape<sup>47</sup>.

The parent advocacy group dsdfamilies overall, and many gynaecologists, indicate that dilation should be attempted first, before any surgical procedures, and '*when the patient is psychologically motivated and a full partner in the procedure*', and this is backed up by the 2006 Consensus Statement. Gynaecologist Sarah Creighton writing for dsdfamilies indicates the importance of waiting until emotional maturity is achieved, stating that:

*Dilation should only be started when your daughter wants to create a vagina. She need to be confident enough to insert the dilators and motivated to do them on a regular basis. She does not need to have a partner before starting treatment and many girls and women prefer to create a vagina before entering a relationship. However if she does not have a partner, she will need to dilate the vagina regularly until she is sexually active.*

Research shows that childhood vaginal dilations appear to lead to severe psychological problems, as they can be experienced as bodily violation<sup>48</sup>. Childhood vaginal and neovaginal dilation can result in poor outcomes and this practice has been criticised<sup>49</sup>. The emphasis on only conducting dilation when a young person wishes to create a vagina appears to be key. If young people are properly informed about the full range of sexual expressions that adults can engage in, not just those considered to be a normal part of heterosexual sex (specifically penis-

<sup>46</sup> See for example, footnote 37, above.

<sup>47</sup> Holly Greenberry, personal communication 12.06.2017.

<sup>48</sup> Ehrenreich, N., & Barr, M. (2005). Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of 'Cultural Practices'. Retrieved from: [http://www.law.harvard.edu/students/orgs/crcj/vol40\\_1/ehrenreich.pdf](http://www.law.harvard.edu/students/orgs/crcj/vol40_1/ehrenreich.pdf); Fausto-Sterling, supra note 11, at 86 n.42 (citing Slijper, F. M., & Drop, S. L. (1998). Long-term psychological evaluation of intersex children. *Archives of sexual behavior*, 27(2), 125-144.

<sup>49</sup> Carpenter, M. (2016) *The human rights of intersex people: addressing harmful practices and rhetoric of change*; Reproductive Health Matters. 24:75.; Tamar-Mattis, A. "Medical treatment of people with intersex conditions as torture and cruel, inhuman, or degrading treatment or punishment." *Torture in healthcare settings: Reflections on the Special Rapporteurs on torture's* (2013): 91-104. Retrieved from: <http://interactadvocates.org/wp-content/uploads/2017/03/interACT-Report-for-UNSRT-on-Intersex.pdf> (see page. 14)



vagina intercourse), then they will be more empowered in making decisions that are right for them.

## 2.10 Prenatal Treatment

Other aspects of current medical practice are being questioned by IVSC people. Prenatal pharmacological treatment (dexamethasone) is offered prenatally to women with a family history of CAH specifically to avoid 'masculinisation' of the genitals. Long-term research with this therapy has indicated potential negative cognitive repercussions on the neonate, such as lower levels of cognitive processing after long exposure. There is a need for more long-term research, as it is not clear if this therapy is effectively safe<sup>50</sup>. From the social model of IVSC health perspective, it is problematic even if effective, as it is based on the view that such conditions are pathological.

## 2.11 Terminations

The *Abortion Act* 1967 (as amended by the *Human Fertilisation and Embryology Act*) sets out the law governing terminations within England and Wales and Scotland<sup>51</sup>. Section 1(1) permits abortion under the following circumstances:

- (a) Where the pregnancy has not exceeded twenty-four weeks and the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family;
- (b) Where the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman;
- (c) Where the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or
- (d) Where there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

It is possible for IVSC fetuses to be terminated under this Act. Indeed, given the over-medicalisation of intersex variations as *Disorders of Sex Development*, it is entirely possible that IVSC fetuses could classify as a 'physical abnormality' under s 1(1)(d) *Abortion Act* 1967 and thus be terminated right up until their due date. Fetuses with IVSC are often terminated where sex chromosome abnormalities exist<sup>52</sup>. This raises very difficult questions regarding the rights of parents, the rights of unborn children, and the way in which a group of people are being systematically erased from existence via terminations. Numerous IVSCs have no documented health impacts<sup>53</sup>.

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<sup>50</sup>Meyer-Bahlburg, H. F., Dolezal, C., Haggerty, R., Silverman, M., & New, M. I. (2012). Cognitive outcome of offspring from dexamethasone-treated pregnancies at risk for congenital adrenal hyperplasia due to 21-hydroxylase deficiency. *European journal of endocrinology*, 167(1), 103-110.; Hirvikoski, T., Nordenström, A., Wedell, A., Ritzén, M., & Lajic, S. (2012). Prenatal dexamethasone treatment of children at risk for congenital adrenal hyperplasia: the Swedish experience and standpoint. *The Journal of Clinical Endocrinology & Metabolism*, 97(6), 1881-1883.

<sup>51</sup> Note that Northern Ireland is not covered by this act. Although note that Northern Ireland is governed by the *Criminal Justice (Northern Ireland) Act* 1945 which has much stricter provisions in place. Abortion here is generally considered unlawful and only permitted whereby the mother's life is at risk.

<sup>52</sup> Jeon, K. C., Chen, L. S., & Goodson, P. (2011). Decision to abort after a prenatal diagnosis of sex chromosome abnormality: a systematic review of the literature. *Genetics in medicine*, 14(1), 27-38. Retrieved from:

<http://www.nature.com/gim/journal/v14/n1/full/gim0b013e31822e57a7a.html>.

<sup>53</sup> See for example <https://www.hfea.gov.uk/pgd-conditions/>

Contributors discussed the issue of termination in different ways:

*We do get quite a lot, well quite a lot, we do get some enquiries about this, so we deal with that as they come in and we've been very heartened to see that most people who get in touch with us carry on with their pregnancy. We also have a bit on the website about it and we try to educate the doctors in particular, because that's generally where the negative information comes from (Representative, Klinefelters Syndrome Association).*

*...the HFEA Guidance, Human Fertilisation and Embryology Authority Guidance on it is just, it's just, you know, fascinating and what they can screen for and it categorises it so much as an illness, whilst at the same time prohibiting sex selection. So you can't choose whether or not it's a male or a female, but you can choose this because it is a disorder, or it is an illness (Representative, Genital Autonomy).*

One of the policy stakeholders emphasised the need to provide good information for expectant parents and families. There is a strong push for reform of policies concerning the termination for IVSC fetuses from some other stakeholders, as shown in the following interview section from the representative of the Equality and Human Rights Commission:

Respondent: *...selective abortion of Intersex people is torture a cruel and inhumane and degrading treatment and unnecessary, completely unnecessary.*

Interviewer: Yeah, thanks, what would you say to people who talked about some of the conditions, Klinefelter's in particular I'm thinking of, where there's also a link with, well a small link with some intellectual disabilities? Would that statement also count then as well?

Respondent: *Absolutely it would, yes.*

Interviewer: Yeah, so do you, I mean from a [legal] perspective, am I right in thinking that those [IVSC] conditions ought to be removed as one that has a criteria for late selective abortions?

Respondent: *Absolutely.*

To summarise, the issue of selective terminations based on sex requires attention by policy makers, practitioners, and NGOs (including Intersex NGOs), working in the field of reproduction, and more widely.

## **2.12 Psychological Services**

This research indicated the importance of psychological services being made available to IVSC people, and findings are backed up in the literature<sup>54</sup>. This is particularly important at the point of diagnosis (for the parents and families of babies and children, and for adults who are diagnosed later in life) but is also for IVSC people generally later in life. The healthcare professional who contributed to the research explained that parents and other family members can be helped with anxiety about IVSC; their anxiety is the problem, rather than the size of (for example) a child's clitoris. IVSC representatives indicate a need for better psychological services, in particular:

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<sup>54</sup> Bennecke, E., Werner-Rosen, K., Thyen, U., Kleinemeier, E., Lux, A., Jürgensen, M., & Köhler, B. (2015). Subjective need for psychological support (PsySupp) in parents of children and adolescents with disorders of sex development (dsd). *European journal of pediatrics*, 174(10), 1287-1297.

*I have also been active in...pushing for specialised clinical psychology services at the point of diagnosis, especially for new parents, there is NHS money for gender reinforcement surgery but not for psychology, which would arguably achieve better results. I think this is still sadly lacking (A representative of AISSG UK).*

The need for ongoing psychological support is also highlighted. This is because of the need to help people who have undergone traumatic treatments in the past and who suffer from post-traumatic stress due to this. Psychological support can also help to alleviate social isolation.

At present, there are deficits in psychological care and a need for psychosocial care models to be implemented, rather than surgical care models. Specifically, a lack of psychological support for people with IVSC in Adult Care is reported. Overall, more training is needed for therapists and higher levels of support are required.

*There seems to be a lack of psychological assessments in Intersex people, especially after surgery, you know, after the bodies have been altered, they kind of, you know, put a Band-Aid on it and pat you on the head and send you away and you know, just cross their fingers that the experiment worked. But you know, we know, through lived testimonies, though, you know, speaking to families of people that have been affected, it's not just the individual that is affected, it is, you know, the families as well and it seems to be a running consistent thing, but there seems to be a lack of support afterwards as well... (Dawn Vago, Intersex UK).*

The importance of peer support is emphasised in these research findings and in the literature<sup>55</sup>. Some of the organisations that contributed to this study are working directly with families in supportive ways. For example, a contributor representing a Klinefelter's group described how they organise peer activity weekends for people affected by XXY; these help to build self-esteem, a sense of community, and social skills. The need for supportive social space for people with IVSC was highlighted by several contributors, for example:

*I think that was my kind of Eureka moment that was the moment that my life changed, when I went to a support group. I think it's a shame that there isn't one out there now, because it was really when I met other Intersex people that I finally felt like I belonged and I really want to take that forward, I really want to create a safe space where Intersex people can get together and just be...(Dawn Vago, Intersex UK).*

Developing better psychological services entails the following: support for peer-led interventions and support groups, more specialised mental health practitioners and clinicians, and training for more generic health practitioners who may come across IVSC people in the course of their practice (see below), so that they can be appropriately supportive.

### **2.13 Support for affected families**

The research findings show that support for those affected by IVSC, including parents, carers, and wider families and communities, is extremely important. This is partly because of the pressures placed on parents and others to define their child as 'a boy or a girl'.

*We absolutely understand that if an Intersex baby is born, there's a huge societal pressure on the parent, you know, have you had a boy or a girl and sometimes it's not*

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<sup>55</sup> Baratz, A. B., Sharp, M. K., & Sandberg, D. E. (2014). Disorders of sex development peer support. In *Understanding Differences and Disorders of Sex Development (DSD)* (Vol. 27, pp. 99-112). Karger Publishers; Hiort, O., & Ahmed, S. F. (Eds.). (2014). *Understanding differences and disorders of sex development (DSD)*. Karger Medical and Scientific Publishers. pp. 99-112.

*as simple and clear cut as that. So there's a lot of societal pressure on the parents...* (Representative of the Equality Unit, Scottish Government)

*...people need to feel safe in society, parents need to feel safe in society, to allow their child to exist as they do, as long as there's not an actual health issue, that's, you know, but that's a question in itself, because things are being described as urgent health issues that need surgery, which don't* (Valentino Vecchietti, Intersex rights activist, independent academic, and author).

It seems that current medical practice may be another reason why things can be so difficult for affected families. This raises important questions about how medical practice and the wider health care system can inform and support parents in the best possible way.

*...to say to parents, you've had a boy, beautiful baby boy and then not far down the road, someone comes and says 'we think your child would be better if it's brought up with, if your child was brought up in a female role'. The parents are completely trashed by this...* (Dr Jay Hayes-Light, Director, UK Intersex Association).

As one contributor noted, it is important not to frame parents as being solely responsible for medical decisions<sup>56</sup>. Acknowledgement is also required of tensions between the rights of parents, some of whom may want medical interventions to 'fix' sex diversity despite the risks to reproductive and sexual functioning later in their child's life, and the best interests of the child. The issue of legal and emotional support for IVSC children is highlighted by contributors<sup>57</sup>. As one of the civil servants noted, this issue sits within a broader social and political context in which there are debates about *'when does the rights of the child and the voice of the child begin to supersede any responsibility and the rights held by the parent.'*

There is a need for greater support for families and children affected by IVSC. This includes information provision by medics and psychological support (see above) to help children and teens who have variations of sex characteristics to accept their bodies and feel positive about themselves. Peer support from IVSC NGOs and advocacy groups is described by contributors as being extremely important, for example in countering isolation. IVSC-led NGOs are able to provide information, for example to counteract the view that a child growing up with a very small penis will, as one research contributor noted, *'suffer dreadfully'* which is *'absolute rubbish...where is the proof?'* (Dr Jay Hayes-Light, Director, UK Intersex Association).

*I think there are still issues around either young people or people in their teens, there to be a lot of pressure and not much support and other issues for parents in a similar way, when someone's a very young child. But I think up to adulthood, at an older stage, they're not ready to assert themselves and it can be overwhelming being told that you're Intersex at that age and then you find there's no support, through peer support or anything like that...* (Annie MacDonald, representative of Trans Media Watch).

*...they're healthy kids. They have the right to function, you know, in sport, in education, in life, in family and in their future lives and who can ever state when a new born baby is born, what that child and who that child will grow up into, we can't. And no irreversible surgery or harmful practice without free and informed consent will ever achieve this. Stop practicing, start listening to intersex people. We know your angst and can help you* (Holly Greenberry, Intersex UK).

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<sup>56</sup> Holly Greenberry, Intersex UK, personal communication 12.06.2017.

<sup>57</sup> For example Holly Greenberry, Intersex UK, personal communication 12.06.2017.

The healthcare professional who contributed to the research described how their team provides support for the whole family, including in some cases grandparents and other siblings. A range of healthcare professionals are involved in this, including nurses, health visitors, and psychologists. The support given includes help with the logistics of living with IVSC on a day-day basis. The health professional also emphasised the importance of supporting the whole family in decision making, when interventions such as surgery and hormone treatment are being considered for older children.

*...the parents' wellbeing is going to have such an impact on their ability to parent and their wellbeing, therefore the wellbeing of their child as well as anything else, that we want to do everything we can early on to support that, because otherwise those, then we layer on the decision making and if they have not had the opportunity to process and make sense of where they are emotionally, that just overrides everything... some children will need and or want to have some treatments, in order to feel healthy physically, not just physically, aside from psychologically and to do that, they need to build a relationship with the team they feel that they can trust and grow up with and are going to get the care that they need. Again, that's like any other family, but with the extra layer of the complexity of what DSD brings I suppose...*

The healthcare professional noted that effective referral methods for supporting families living out of the immediate area of the clinic are also important. This contributor described difficulties when parents do not accept psychological help in supporting their child with IVSC, and expressed the opinion that there are limits to what the team can do about this. One of the other contributors suggested that *'this is about the parents needing to change, not use the child as a tool for social consent'*<sup>58</sup>.

IVSC activist and patient advocacy organisations also discussed the way in which they support children, young people and families affected by variations of sex characteristics. Some contributors felt that support should be provided away from medical settings and patient groups, because of the current difficulties with medical provision. For example Dawn Vago from Intersex UK discussed the importance of Intersex NGOs supporting those affected by IVSC without bias, with surgical procedures being deferred until an IVSC person can decide for themselves if they need interventions. Others, specifically patient and parent advocacy groups, work with medics and with families to provide support. The findings indicated that both types of support are appreciated by families affected by IVSC (although one contributor stated that the support from patient and parent advocacy groups is mostly support provided after surgery<sup>59</sup>). The first of the following quotes shows how Intersex NGOs can be seen to support families affected by IVSC, and the second refers to the parent-run organisation.

*We...have some families contacting us or some children, or you know, young adults contacting us and thanking us for allowing them to believe that they exist and then it's all worth it* (Dawn Vago, Intersex UK).

*I knew from being connected to other parent groups that so many parents have the same issues, share the same worries, they say, you know, 'how do I do this [raise a confident and happy child], how do I cope socially, because I have to protect the identity of my child, I'm lonely and scared [about what the future will bring for my child]'* (Ellie, Founder member of dsdfamilies speaking in private capacity).

A further issue is that of long term damage to IVSC people who have experienced medical interventions that they find regrettable. Because parents are the people who provide consent for these interventions to take place, it is possible that the IVSC individuals may blame them

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<sup>58</sup> Dawn Vago, Intersex UK, personal communication 12.06.2017.

<sup>59</sup> Dawn Vago, Intersex UK, personal communication 12.06.2017.

if the results are damaging. Also, it can be imagined that parents may find it extremely difficult to explain the need for medically unnecessary interventions that may be painful and disfiguring to children and young people. The research findings indicate that people with IVSC can have difficulties in later life. Early negative experiences can impact severely on relationships with parents<sup>60</sup>.

*I know from the adults how difficult it has been to come to terms with their own bodies and how difficult relationships still are. There are some adults my age who still don't have, or who just never had a normal loving relationship with their parents and these parents who, I don't know, simply didn't understand what it was that their kid had (Ellie, Founder member of dsdfamilies speaking in private capacity).*

One contributor remarked that the difficulties that IVSC people have coming to terms with their bodies only occur after surgery and because of a lack of emotional care and support then<sup>61</sup>. As noted above, psychological support may be important in helping those affected by IVSC and by unnecessary interventions in their pasts. It is important to distinguish here between emotional support that can help IVSC people to manage their situation in a society that can still be very narrow and traditional in its assumptions about sex differences, and emotional support that is reparative, and that could be avoided if the intervention/s had not happened in the first place. Overall, he argued that the good work being conducted in medical settings to support families affected by IVSC needs to be continued. More work is needed to support families, including helping parents to address pressures concerning stigma and isolation. IVSC support groups and parental support groups can play a key role in supporting families.

### 3. Clinical governance

This section of the report focuses on ways to improve the healthcare of IVSC people in the UK. It addresses the medical establishment as an institution, and practice across different parts of the NHS. The creation of excellent, patient-centred healthcare is central to NHS provision. None of the research contributors discussed private healthcare, but some of the issues indicated in the research are likely to be relevant to private providers.

#### 3.1 Wider healthcare issues

Contributors identified problems with a lack of knowledge and awareness about intersex and IVSC amongst medical practitioners generally, including general practitioners. There may be a lack of awareness amongst some other healthcare professionals such as nurses and midwives.

Specialist services such as those providing mental healthcare may be underequipped to deal with issues brought by ICVS people, who may be suffering from problems such as post-traumatic stress syndrome. More research is needed to uncover potential healthcare deficits. In this research, a contributor reported cases of IVSC people having negative experiences in hospital when they present for their procedures. The lack of awareness about intersex can also impact on IVSC people's willingness to discuss health issues with their GP. This may be a particular issue for young IVSC people, as young people may in general find talking about their bodies to medical practitioners to be unnatural<sup>62</sup>. There appears to be a need for better awareness of the issues amongst general practitioners:

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<sup>60</sup> D'Alborton, F. (2010). Disclosing disorders of sex development and opening the doors. *Sexual Development*, 4(4-5), 304-309.

<sup>61</sup> Holly Greenberry, Intersex UK, personal communication 12.06.2017.

<sup>62</sup> Holly Greenberry, personal communication 12.06.2017.

*... if you're just going into General Practice as a doctor and you have very little information or have been provided with no information [sic] on Intersex issues, you know, the chances are you're going to come into contact with somebody who is Intersex at some point during your career, you know. If you have that little information, how can you effectively, you know, treat and even to converse with somebody who is Intersex? (Joe Holliday, Intersex UK).*

*I think that there is still a huge amount of ignorance amongst GPs in particular about the condition and I think there is some, a better understanding, amongst endocrinologists. But I think that if I was to turn up at a GPs surgery today, showing all the classic symptoms, there's still a good chance that nobody would notice (Paul D, Klinefelter's Syndrome Association).*

Some IVSC people discuss a lack of longer term care. Not enough is known about the impact of interventions such as hormone treatment on intersex people as they get older, and provision can be lacking (see also section 2.8):

*I know that some of the medications have long term health effects and cause problems, and, you know, can effect bone integrity and things, I don't know the extent it will affect my own healthcare, or other people's, you know, but I wonder myself, and it is, it's a scary thing, it's like not seeing a clear pathway ahead of me... isn't always easy to access good medical care because if I, as you know, as happened recently, I was quite ill and then if people don't really understand your physiology...medically, then it's complicated, and it's complicated trying to explain things, it's complicated being a body that is different in, you know, in a very gendered healthcare system (Valentino Vecchietti, Intersex rights activist, independent academic, and author).*

*....thinking about testimonies from other people, other Intersex people, I mean, the anxiety to access medical care, for example, in the future, the anxiety around and the appropriate medical care when you're an older person. So there might be a need for extended HRT, there might be a need for more readily accessible support, if you've never been supported, or if you've only just been able to acknowledge to yourself and start repairing the emotional damage and psychological damage you've experienced... (Holly Greenberry, Intersex UK).*

Some contributors discussed a need for effective healthcare provision for people with IVSC in later life. They may have undergone surgery but then drop out of care pathways. Other areas requiring attention include the risk of some IVSC individuals developing cancer due to physical conditions; they need to have access to regular screening and support.

### **3.2 NHS resourcing**

Difficulties with the medical care of IVSC people relate in part to broader issues to do with NHS resourcing and the way that it is managed.

*I don't think it's been top of their list of priorities and I don't think they've, I think obviously what concerns our health colleagues at the moment is very much the big ticket items...dementia and things like that. I think the rarer stuff is possibly not always top of their agenda for understandable reasons...the pressures of dealing with the NHS, so in that sense, that's a challenging task...I think the focus obviously is on the issues that affect large numbers of the population and on things like waiting lists and things like that. (Representative (1) of Scottish Government).*

*...where gendered healthcare, you know, fails people of difference, is that it can't accommodate scans or monitoring easily, and so it's easier for them to remove organs*

*that they might need to scan or monitor, than to allow spaces for us to exist safely in the system - and it sounds awful when I say that out loud, but that's the truth in my experience* (Valentino Vecchietti, Intersex rights activist, independent academic, and author).

The issue of pressure on the NHS is certainly an important one. Questions need to be asked about why unnecessary surgical procedures and other treatments are being paid for out of the public purse. More economical psychological and social interventions may also be more effective long term in supporting the wellbeing of intersex people and those with IVSC. There is a lack of clarity about how many procedures are taking place, of what type, and at what cost to the NHS. It appears that an accurate assessment of the cost of current DSD/IVSC treatment protocols/practices is urgently needed. This should assess the cost of infant and childhood surgical procedures and other interventions such as hormones, after-care costs, and ongoing potentially unseen costs of medical support such as treatments for post-traumatic stress disorder. Assessment of the costs of different treatment pathways for patients who are able to give informed consent is also important, but the cost of treatments that are seen as necessary by these patients should not be a barrier to delivery of treatment.

### **3.3 The lack of data and evidence**

The research raises concerns about the adequacy of data regarding the types of interventions currently being practised, at what ages, and with what type of informed consent provided by the child, if any. Whilst the available data show that IVSC and DSD surgical procedures – both those necessary for basic functioning and those that are not – are currently being practised (see above), it is not sufficiently detailed to provide an adequate picture of the situation. There is a lack of knowledge about childhood interventions that may be experimental, and their effects. It appears that a clinical audit is urgently required to support good patient care and also to ensure that public funds are not being wasted on unnecessary medical interventions. The NIHR could usefully consider commissioning research to provide the evidence base and more information about current practice. IVSC people report a dearth of robust evidence in the field:

*It's so unscientific, because they haven't collected the data. I wonder, you know, from a healthcare perspective, how could it be that there's no funding to collect data? Which people have talked about. It's very hard to get funding when you're an invisible group. A lot of people have said it's an ethics thing; they don't want to ask people, because ethically parents don't want their child to know that they're, you know, that they have Intersex Variations. There's all these ethical loopholes to go through, even to get data, or to interview, and I think that's a problem, and a lot of those are, a lot of the ethics things are rooted in people's fear of prejudice, people keeping things from the individual who has the Intersex Variation* (Valentino Vecchietti, Intersex rights activist, independent academic, and author).

*I mean it's so difficult to get the actual, the actual figures and the numbers. Doctors become very, very evasive when you ask them about the topic* (Dawn Vago, Intersex UK).

Alongside a need for data quantifying the types of interventions taking place, what ages they are taking place at, the type and level of informed consent gained, and their cost (immediate and longer term), there is also a need for more research to improve patient care. For example, more research is needed into the long term effects of interventions, such as the impact of hormone therapy on bone density and cardiac health. A few contributors discussed a need for greater understanding of the medical and social issues facing IVSC people over their life-course.



One contributor noted that the push for research should not override the provision of effective care to IVCS people and their families.

*I know that doctors are just as keen to get data, to help them understand how to improve care. So hey, activists and doctors have perhaps more in common and that's great, but we can't wait! Ultimately there is still that every day care and we need to have that information and frankly until somebody does that [translate data/research into practical and accessible support], then the parents are still left fending for themselves. The lack of support about how to raise and talk to their child, or what to do with all this surgery business remains. So yes, I'm sure, I'm sure data is really important, but not at the expense of all the other stuff...(Ellie, Founder member of dsdfamilies speaking in private capacity).*

Overall, there is a need for a National Review of Intersex and Variations of Sex Characteristics Policy and Practice. Contributors discussed a need for data about interventions to be systematically gathered and made public. Accessing the expertise of the intersex NGOs who have been conducting advocacy and human rights work in this field for a long period of time will be important for future research. Research and better patient care go hand in hand, and more work is needed in both areas.

### 3.4 Clinical Protocols

A number of protocols and guidelines are in place to support the care of IVSC people, in addition to the 2006 Consensus Statement discussed above. Some of these relate specifically to early interventions regarding IVSC infants and children. In some cases, protocols were not immediately apparent, for example in the cases of the Royal College of Medicine and Royal College of Surgeons, and further enquiry is needed. Overall, medical guidelines remain ambiguous regarding the very sensitive issues relating to DSD and IVSC interventions, which may then create difficulties in clinical governance.

There are some guidelines available from the Royal College of Endocrinologists<sup>63</sup>, however these relegate decision-making power to parents and do not clearly indicate non-surgical pathways. Some clinicians in the field advocate a cautious approach, allowing for the possibility that 'Some parents may consider early genital surgery as a mechanism that could possibly protect their child from the risk of future stigma', and that 'This will require a thorough discussion with several members of the MDT team including the clinical psychologist, surgeons, gynaecologist and nurses so that the parents are fully informed of the controversies around undertaking or withholding early genital surgery'<sup>64</sup>.

The Royal College of Obstetricians and Gynaecologists indicates in its ethical recommendations that 'Owing to anatomical development during puberty, FGCS [female genital cosmetic surgery] should not normally be offered to individuals below 18 years of age<sup>65</sup>.' However, it also indicates that FGCS 'refers to non-medically indicated cosmetic

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<sup>63</sup> Society for Endocrinology: Clinical Practice (n.d.). Retrieved from: <https://www.endocrinology.org/clinical-practice/clinical-guidelines/>

<sup>64</sup> Ahmed, S.F., Achermann, J.C., Arlt, W., Balen, A., Conway, G., Edwards, Z., Elford, S., Hughes, I.A., Izatt, L., Krone, N., Miles, H., O'Toole, S., Perry, L., Sanders, C., Simmonds, M., Watt A., Willis, D. (2015). Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development. Clin Endocrinol (Oxf). 84(5), 771-88.

<sup>65</sup> Royal College of Obstetricians and Gynaecologists Ethical opinion paper Ethical considerations in relation to female genital cosmetic surgery (FGCS). <https://www.rcog.org.uk/globalassets/documents/guidelines/ethics-issues-and-resources/rcog-fgcs-ethical-opinion-paper.pdf> (last accessed 18.09.2017).

surgical procedures', highlighting the complexities of why and when genital surgeries are to be considered 'medically indicated'.

The European Society for Paediatric Urology and the Society of Paediatric Urology of the United States are less certain that surgeries should be delayed, indicating the risks of 'untried and unevaluated major reconstructive surgery at adolescence a highly stressful period of psychological development<sup>66</sup>'. Clinicians indicate awareness that 'Recent controversies regarding DSD management have involved: The long-term outcomes of early reconstructive genital surgery with reportedly poor cosmetic and functional results. The irreversibility of the reconstruction. The absence of consent from the young patient in a major decision for his or her future. Secrecy or incomplete disclosure of relevant medical information to patients<sup>67</sup>'. The ESPU/SPU standpoint indicates both a lack of data regarding psychosocial outcomes of early surgical interventions and/or a clear position in this regard, instead stating 'Each patient and each situation is different and it is the role of the multidisciplinary team to individualize the treatment to the patient and family<sup>68</sup>'.

It was unclear from the research findings presented in this report as to whether organised clinical networks are in place across the UK to support the implementation of the 2006 Consensus statement and other protocol statements. In Scotland there is a Managed Clinical network. The healthcare professional who contributed to the research raised concerns that there is a lack of agreed protocols and practice regarding IVSC in contrast to other areas of care, and insufficient professional networks. Findings indicate a need for more knowledge about current policies and their implementation:

*...my understanding there isn't specific clear policy within the British, or the UK-wide NHS services in any of the UK countries that specifically detail the full variations of sex characteristics and the treatment protocol, or the care protocol, for those people. If you look at GMC Guidelines, they are flouted and do not, they are the best policy guidelines in a generic sense to guide medics on the treatment of certain groups of people, broadly speaking and if you look at Intersex individuals, or people born with variations of sex characteristics, you will see that those guidelines are completely ignored by a small cohort within the medical profession, which I think actually is an embarrassment to the greater good that function and are regarded within the medical profession and the NHS and none of us would ever deny the NHS wasn't a phenomenal organisation (Holly Greenberry, Intersex UK).*

With respect to the coordination of treatment for people with IVSC, practice appears to be patchy, according to the perceptions of some contributors. Clinics may operate in isolation from each other without sharing good practice, perhaps because of a culture of secrecy around this field.

*...there are more surgeons and psychologists and that...are on our side and are doing their best to implement changes. But like I said before, it is very much where you find yourself and who you find yourself talking to...(Joe Holliday, Intersex UK).*

*I think there needs to be, yeah, better joined up regulated care across the country, there needs to be better resource, but I don't think it should be in one centre. But yeah, I mean actually understanding what the [expletive] people are doing for a start would be good...(Healthcare Professional, NHS)*

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<sup>66</sup> Mouriquand, P., Caldamone, A., Malone, P., Frank, J.D., Hoebeke, P. (2013). The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD). *Journal of Pediatric Urology*, 10 (1), 8-10.

<sup>67</sup> As in footnote 63.

<sup>68</sup> As in footnote 63.

### 3.5 Conflicts concerning Care Pathways and Ways Forwards

The healthcare professional who contributed to the report discussed the difficulties facing the medical establishment regarding care for people with IVSC (as noted above this is currently termed DSD within medical contexts) in some depth, reporting that:

*I think we're all in a dilemma about how we continue to practice...how we as a team continue to practice in the context of what we read and hear and think about and it sets up all kind of dilemmas. So in terms of yeah, there is the consensus document and other guidelines and you know, there is, you know, there's other research out there that would give you guidance as to how to do, but the big thing at the moment is, in terms of human rights and ethics and decision making, is I think the main thing and for me, the big thing is that either way, families are living with massive dilemmas in terms of if they do or don't have treatments, or whatever, just life, living with an Intersex condition and DSD, you know, even aside from all of that medical bit, just life. So I guess for me, that's the big kind of, for the team to feel like they are, we are all doing the best that we can do for these young people and families.*

As indicated earlier, a comprehensive review or inquiry, and more research, is needed to understand the issues more fully. This one contributor described high levels of anxiety amongst some clinicians about the claims that IVSC people are putting forwards, which have important implications for both past and current medical practice. They may perceive IVSC human rights activists as being adversarial, when overall these groups are just trying to influence practice that they experience as very damaging. Medics' anxiety could be one of the main reasons why some appear to be wilfully ignoring the voices of people from the groups that they are supposed to be caring for.

*I think that the medics kind of do a horrible intake of breath when you talk about IGM. Like, when I talk about it, like when I come out to the team and go 'hey guys', [nervous laugh]. I was at a meeting recently, you know, IGM, 'you should not be doing it then', [laughs]. It's like, 'what?', so they're just like with hypospadias, 'no, that's not what we do, no, no', so that's the response to that bit. I think they struggle with the whole, the whole child body autonomy to the parental thing, I think they struggle with that because of their way of thinking, that is all structured around parental responsibility, informed consent, that's what we do, so then they're like ah, how, what, but even that's a bit, that's difficult to deal with within the ethical, you know, they'd say, you know, respect the child, but then we have to respect the fact that this is their parent and they do make decisions for them all the time.... these surgeons are human beings and they have gone into this practice to, you know, they have sworn to whatever they do, the medical things, that they, that they're there to heal, to help, to whatever and to be then accused that they are butchering, that [gasps anxiously] it just cuts to the core of what the hell they're doing and so they're just, you know, it's so challenging, that and it's scary for them, it's scary for them. (Healthcare professional, NHS).*

The anxiety that some medics may experience may be one reason for what appears to be a lack transparency and accountability in this field. One contributor has the perception that medical interventions are not being properly recorded and reported that forced sterilisation procedures currently being 'hidden' within other procedures. This could mean that they do not show up on medical records and within broader monitoring processes at hospitals and nationally. This perception may well be untrue, as commissioning interventions requires accurate reporting, but the research findings indicate a need for greater transparency and accountability.

*It amazes me that there are hospitals, children's hospitals, who remove surgery, who remove procedures from a surgical heading, if the procedures aren't on a child's [external] genitals. So you can perform a gonadectomy and its not considered surgery, so the data becomes skewed. That is, I believe, neglect and I believe that's abuse of the system by professionals who are paid by tax payers...(Holly Greenberry, Intersex UK).*

*...there's also the secrecy and you know, the cover ups that often go on in terms of the surgeries and what happens to these children. They're often left in the dark...its misinformation, its hiding, you know, certain things about people and it's such a common thread of those who are Intersex, this whole secrecy and almost like a medical cloak and dagger approach to treatment of Intersex people... (Joe Holliday, Intersex UK).*

*...if you look at the official documents, for instance, they tend to say that there are no instances of regret in most cases. Where we found multiple instances of regret from surgery that's been going on. So we're sort of trying to make them alert to the fact that they shouldn't take doctors' testimony as the main authority, just because they're used to listening to doctors and that they should be listening to everybody and they have to balance that properly...(Annie MacDonald, representative of Trans Media Watch).*

Taking the concerns of ICVS people on board and changing policy and practice may be difficult for some medics, who are used to things being done in a certain way and who have considerable power and prestige. There is willingness from IVCS activists to work productively with medics to foster positive change. Some organisations already have positive relations in place with supportive medics. IVSC organisations are keen to find ways forward, despite the challenges.

*...we can't demonise the medical profession...because we need to work with them to create the change, and so it must be that if we back people into a corner, their hackles are raised and they're not going to give: they're going to fight back and be defensive. It can't be that. It has to be that there's a sense of collaboration within the medical profession: where we are trying to move towards the same page, because we need allies, not adversaries, and I think that's a tough thing, a tough ask for people...(Valentino Vecchietti, Intersex rights activist, independent academic, and author).*

### **3.6 A lack of engagement with Intersex people and those with Variations of Sex Characteristics**

There are examples of good practice concerning patient engagement amongst clinicians working in this field. For instance, the healthcare professional who contributed to the research said that they contacted a range of intersex NGOs and advocacy groups to ask for their input when their clinic was developing a new service. Positive practice is also found amongst some organisations, for example members of the Klinefelter's support group going to conferences for GPs, Endocrinologists and Nurses and publicising their group and its concerns. It appears that many clinicians do refer people with IVSC and parents of babies/children with IVSC to specific groups such as dsdfamilies, as specified in the Society for Endocrinology guidelines and 2006 Consensus statement. However, it should be noted that dsdfamilies is a parent-run group, not a patient advocacy organisation or intersex NGO.

The research showed that there is a perception of a severe lack of engagement with IVSC advocates and individuals by clinicians who are involved with developing service provision.

For example, Intersex UK has not received a single referral from medics working in this field<sup>69</sup>. The IVSC contributors describe being ‘shut out’ of discussions about care.

*...there has been a close down, I would say, within medical practice, of the will to engage and that with Intersex Human Rights organisations or Intersex research projects, by medical practitioners, who specialise in using their terminology in DSD or Intersex, and that concerns me because the, because such people should be questioned and should, as professional intelligent individuals, should be, as civil servants actually, as paid by the tax payer, should be held to question over the very procedures which are massively questioned and condemned by many, many people who have experienced these treatments, yet they still go ahead...(Holly Greenberry, Intersex UK).*

*...the medical establishment needs to really be listening to Intersex people, which is not something that I feel is happening on a sort of equitable basis at the moment...(Annie MacDonald, representative of Trans Media Watch).*

A few contributors discussed tokenism and the use of malleable, unrepresentative patients or parents on boards by medics keen to show that they are consulting with IVSC people. Whilst consultation with parents is important, the lack of consultation with IVSC people is seen as very problematic by the IVSC contributors to this report. In some instances, there seems to be a lack of involvement and consultation with IVSC people altogether. Issues of rhetorical or ineffective consultation may be relevant in other areas of healthcare. Here, it is particularly worrying because of the ways in which non-consenting infants and children are subjected to irreversible treatments which have life-altering implications for their future identities, health, relationships and families.

Contributors also raised concerns about a lack of day-to-day liaison with IVSC groups and others advocating for people with IVSC. For example, the healthcare professional remarked that colleagues do not consistently provide information about support groups (apparently some individuals are better than others, and some support groups are mentioned more frequently e.g. Living with CAH). Colleagues certainly do not give information about IVSC advocacy or activism groups<sup>70</sup>. This means that families cannot access the resources that these groups can offer unless they find them independently. The research also indicated a need to recognise that people with IVSC and their families may find it hard to articulate their interests, when faced with medical authority.

Contributors made many useful suggestions about possible ways of improving clinical governance in the IVSC field. These are reflected in the discussion above, and some of them are evident in the quote below:

*I think what needs to happen is health and social care authorities need to engage directly with Intersex organisations and involve them in their decision making processes around surgery and hormonal treatments. I think they need to ensure that they balance out the impact, because of course they're going to be, they're going to lead the parental decisions on a medical model approach and it's not dissimilar to how we see disabled people and LGB people, where people are treated in a service which doesn't, you know, that doesn't involve or understand what would be a social model approach and I think we've seen great advances around disability and LGB, where health services have engaged communities. (Representative, Equality and Human Rights Commission).*

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<sup>69</sup> Holly Greenberry, personal communication 12.06.17.

<sup>70</sup> Healthcare professional, personal communication 20.07.17.

As part of improving care, professional training and development seems needed. This is so that medics and healthcare professionals, including nurses and midwives, are able to fully understand the need to preserve children's genitals until they are able to make informed decisions, and to negotiate with parents to make sure that this happens. It also includes provision to help them come to terms with the damaging effects of past medical practice, no doubt carried out with the best of intentions in a society that has previously been very rigid in what was seen as 'normal' sex characteristics. Clinical governance priorities are outlined below:

*I would put non-consensual surgery [as the key issue for attention], because once that is done, there is a problem for that child for the rest of their, for most of them, not all, but for most of them, that creates problems for life. A very close second to that is re-educating, reforming the attitudes of the medical profession and **its very, very simple, you just refer to the Hippocratic Oath – first, do no harm** (Dr Jay Hayes-Light, Director, UK Intersex Association).*

Overall, there appears to be a lack of coordinated and transparent, clinical governance in relation to IVSC (termed DSD in medical settings) care, but more substantial research is required to assess the situation. As suggested above, the findings indicate a need for review of practice, protocol, and data-gathering, in relation to medical procedures used with IVSC children and adults. It is not apparent as to whether the Care Quality Commission<sup>71</sup> has ever reviewed service provision in this area.

## 4. Legal Aspects

### 4.1 Snapshot of the issues

The research shows a pressing need for legal reform in the UK regarding IVSC. This section of the report should be read in conjunction with evidence submitted by legal scholars and Holly Greenberry, Director of Intersex UK<sup>72</sup>.

The following quote, provided by a representative of the Equality and Human Rights Commission, highlights a range of legal issues:

*...the UK doesn't permit Intersex people to change sex in law, except by declaring that they're transgender and then following the medical protocols there. That there's no direct protection from discrimination and you know, it's a huge gap and you know, Intersex people's rights to life, as I say, human rights can be violated in discriminatory sex selection, or other forms of testing and you know, that really I would say that there needs to be a full scale review of the law in respect of Intersex Equality, alongside recommendations from the Inquiry [regarding transgender] that the Equalities Committee made, in order to create better opportunity for greater protection for people's rights. It would be meaningless to leave out a small section of the community, it just wouldn't make sense...*

One contributor pointed out that bodily integrity is central to western understandings of law. In the UK context, autonomy, self-determination and freedom from interference with one's body are vital underpinnings of criminal, tort, family, medical and constitutional law. These principles

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<sup>71</sup> <http://www.cqc.org.uk>

<sup>72</sup> Transgender Equality: Written evidence submitted by: Centre for Law & Social Justice, University of Leeds, and Intersex UK. Retrieved from: <http://www.law.leeds.ac.uk/assets/files/research/clsj/transgender-equality-response-21815.pdf>

have been reaffirmed in international law such as the Universal Declaration of Human Rights and the case law of the European Court of Human Rights. As a result, medical professionals are under strict medical guidelines to act in the best interests of the patient and to try and obtain informed consent. Our research indicates that both of these conditions are being flouted.

#### **4.2 Moratorium on surgery and legal measures to protect infants' and children's bodily integrity**

The ICVS contributors to the research would like a moratorium to be put in place to stop surgical procedures on younger children and babies. Most of the intersex contributors see legislation to stop unnecessary surgical procedures on babies and young children as being required. These surgical procedures include surgical procedures that are purely aesthetic, such as clitorodectomies, and those that cause sterilisation where no immediate threat of cancer or other threats to life are present.

Overall the research suggests that laws to protect infants' and children's bodily integrity are needed except where surgical intervention is necessary for basic functioning. The definition of 'necessary' is varied – several contributors say that surgery on infants and young children should only take place if the condition is critical, and intervention necessary for an individual's survival.

*I think certainly outlawing unnecessary surgery on children is, in my opinion, it's common sense, you know. Nobody should have surgeries performed on them that are not needed. It's just a common sense view, you know, especially surgeries that we know cause more harm than good. You know, I **have never spoken to anybody, myself, that has been happy, had their, you know, genitals surgically altered or that they'd, you know, been sterilised or castrated**, you know. These are not things that people would normally want to happen to them, however because they're too young to agree, its going on and the fact that the medical profession is sort of quite happy to remain almost blind to the issues that those people are facing, they're still happy to go on with what they're doing (Joe Holliday, Intersex UK).*

*...the medical profession doesn't pass laws in this country, Parliament does that. We want a law, we do not want a suggestion, or a recommendation, a moratorium, we don't really want that either. But we'd settle for that for the moment. **What we want is the law changed** (Dr Jay Hayes-Light, Director, UK Intersex Association).*

Some of the contributors, including those who work in the field of intersex human rights, are clear that legislation is crucial to remedying the current situation. This is because it seems that medics will not stop unnecessary surgical procedures on babies and children with diagnosis of DSD unless they are legally obliged to do so. It appears that only legal interventions will effect change in current medical practice.

*...one fairly sort of, shall I say influential and successful, according to him, [medic], who performed these surgeries and does perform these surgeries, his simple answer to being questioned about, you know, what will happen about these surgeries, and in spite of everything that's written in the United Nations Committees Report, he said 'oh, we'll continue', he said **'I shall continue to perform these surgeries'**, he said, **'until its illegal'** (Dr Jay Hayes-Light, Director, UK Intersex Association).*

*...one of the surgeons has said to me **'this needs to be a law, if someone tells me not to do it, I can't do it, and I won't do it.** I think at the time, I went 'so you just don't want to have to make the decision, you just want like, you want someone else to*

*say no, you can't say no, so you want someone else to say no, on your behalf'* (Healthcare professional, NHS).

These startling assertions are reflected elsewhere. In another recent report, a medic is cited as stating that he will continue to conduct surgical procedures until legislation is passed to stop him<sup>73</sup>. Research participants explained that the government has a key role to play in making reforms take place.

*...the NHS is run by the State, the State have the power here to say you can't do those surgeries. Now you know... [international activists] they did a report for the UN on intersex surgery in the UK. The UK, someone came along, I don't know exactly who it was, but they were from the Government. They listened to all the stuff they had to say and they said 'this is an NHS issue, this isn't our problem'. That simply doesn't hold, because the State runs the NHS. That argument wouldn't hold for something like Drug Therapy...the State is so interventionist in so many other spheres. So to disavow their jurisdiction here is really interesting. It's interesting that they choose to do that. But theoretically, there's absolutely nothing to stop them from making these surgeries illegal* (Representative, Genital Autonomy).

In Scotland, there appears to be hesitancy about addressing the role of the medical profession regarding IVSC people. The Scottish government is working with intersex NGOs Intersex UK and UK Intersex Association in developing policy reform. The research findings indicated a possibility that governmental stakeholders may be prioritising the interests and views of the medical profession over those of IVSC people in a problematic way, given the need to focus on the best interests of IVSC children and adults. One of the Scottish stakeholders expressed concern not to be *'heavy handed'* regarding reform, and that avoiding legislation would be the *'best outcome for medical practitioners'*. This stakeholder discussed the need for careful reform that includes the views of all the different people with IVSC in Scotland, and the medics working in the field. A consultation with the public is currently underway.

The findings from this report indicate clearly that there is a need for surgical procedures on infants and children to be stopped (unless they are necessary for basic physical functioning) until they reach the age of being able to give meaningful informed consent, and that there is a lack of transparency about the current situation. However, the findings are based mostly on contributions from outside Scotland, so more research is needed on the Scottish case.

### 4.3 The Equality Act and Anti-Discrimination

The second key area for legal reform concerns the need for legislation to prevent discrimination against IVSC people.

*...nobody should be discriminated against because, you know, of what their genitalia looks like, it's ridiculous and it certainly should be something that is protected. You know, we try and, you know, in our equalities laws and in our, you know, in our protections, we try and include everybody. But unfortunately that's not the case, that's, you know, not everybody is protected actually. You know, but you know, then they'll turn round and say well technically you are sort of protected, but not really, it's*

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<sup>73</sup> StopIGM.org; Zwischengeschlecht.org, Bauer Markus, Truffer Daniela, IntersexUK, Holly Greenberry, Dawn Vago, OII-UK, Leslie Jaye, UKIA, Dr J. Hayes-Light, (2016). Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC) (2016). Retrieved from: [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf) (see pages 9-12)



*not specific to you, but you know, you could be, you know, they might turn round and say 'oh you're protected because, you know, you could consider it a disability or something like that'. So and that's not really right because you're being discriminated against because of disability. So yeah, it's certainly something that needs to be a protected characteristic... (Joe Holliday, Intersex UK).*

Many stakeholders and intersex people who have expertise regarding equalities and human rights are clear that intersex should have been included in the Equality Act 2010 and that IVSC needs to be a protected characteristic. There are specific areas where protective legislation is needed, for example healthcare, employment and delivery of services. The Equality Act is described as 'out of date' because of the omission of intersex people by one stakeholder.

*...it isn't in the Act because it isn't a protected category. Why isn't it a protected category? Well that was the Government that decided that, you see, so it's not, no we didn't decide that, that's the Government has decided that and then you ask the Government and then they pass you onto somebody else...I believe strongly that the reason that Intersex people were not included in the 2010 Equalities Act...is that 'well we don't really know what Intersex is all about' and, you know, 'the medical profession have more or less taken possession of it, so we won't disturb the medical profession, upset them, or question them, because you don't do that'. You should do. But no, so when they debated the 2010 Act, when it was a Bill, then it became an Act, there was no-one there, because no-one had been invited to speak up on behalf of Intersex people and the politicians decided that 'we'll leave that alone because it's a pathology, isn't it', you know, being gay isn't the possession of the medical profession, although it used to be (Dr Jay Hayes-Light, Director, UK Intersex Association).*

Work has been done on including IVSC people under existent European Union Anti-Discrimination Law.<sup>74</sup> However, it is crucial to note that anti-discrimination law must take place in conjunction with bodily integrity. It is not a full solution to the problems faced by IVSC people<sup>75</sup>.

#### **4.4 Birth certificates, Sex Assignment, and Gender Reassignment**

Contributors discussed the problematic situation of people being assigned to a sex on their birth certificate and then not always identifying as this sex when they grow up, and being forced to undergo gender transition to gain legal recognition. The Gender Recognition Act 2004 requires evidence of gender dysphoria in order to transition. The 2017 ICD-CM continues to exclude intersex from this definition, making it exceedingly difficult to provide the evidence necessary to engage with the act. The Gender Recognition Act's reliance on psychological aspects of sex and gender fails to provide a congenital basis that encompasses the needs of IVSC people. The research findings point to a need for legal reform to facilitate intersex people in gaining legal recognition in the sex of their choice.

*...it's the right to not change your birth certificate, but the right to correct your birth certificate and currently that's not possible, for example women with, who have been diagnosed with lower grade partial Androgen Insensitivity Syndrome can't apply to the Gender Recognition, through the Gender Recognition, like for a Gender Recognition Certificate and I do think there has to be an amendment to the legislation to accommodate correction and I think correction is vital because that's about the authenticity of who you are...(Holly Greenberry, Intersex UK).*

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<sup>74</sup> Travis, M. (2015) Accommodating Intersexuality through European Union Anti-discrimination Law, *European Law Journal*, 21(2) 180-199.

<sup>75</sup> Garland, F. and Travis, M. (forthcoming) Legislating Intersex Equality: Building the Resilience of Intersex People through Law.

Clarity is needed about the current situation regarding birth certificate change for IVSC people who wish to identify as a different sex to that assigned at birth. There are some indications that intersex people can gain legal recognition in their true sex, if they are able to provide evidence proving that an error was made during birth sex assignment by medical practitioners. However, the situation is currently unclear, pointing to a need for legal policy development in this area.

*...it should be much easier to be able to right that wrong [mistake in sex assignment at birth], especially in terms of a birth certificate, you know. If a mistake has been made, it should be able to be rectified, but to leave someone with, you know, to leave someone who's identifying as female with a male birth certificate for the rest of their life is quite unfair... (Joe Holliday, Intersex UK).*

Amendments to both the Birth, Deaths and Marriages Act 1953 and the Gender Recognition Act 2004 are necessary in order to facilitate the needs of intersex people without pathologising their experiences. Requiring medical evidence, for example, would be an unhelpful change to the current legislation. There are arguments that separate legislation is required for IVSC people; amendments to the Gender Recognition Act are not sufficient and the Gender Recognition Act is '*not the place for intersex*'<sup>76</sup>.

#### **4.5 Child Protection**

The findings from this study raise questions about whether UK infants and children are currently adequately protected from harm. A range of international human rights instruments and directives aim to protect children (see appendix 3), for example the 2015 Committee on the Rights of the Child<sup>77</sup>.

This section of the report outlines concerns in three interlocking areas: child abuse; torture and inhumane treatment; and mutilation. There is an urgent need for these concerns to be addressed; this report aims only to outline some of the issues that require consideration.

##### **4.5.1. What is child abuse? Are unnecessary interventions on IVSC infants and children a form of child abuse?**

While the World Health Organisation (WHO) defines the key elements of child abuse and neglect as including 'all types of physical and/or emotional ill-treatment, sexual abuse, neglect, negligence and commercial or other exploitation, which results in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power'<sup>78</sup>, the UK currently lacks one clear legal definition of 'child abuse' or 'child maltreatment'. Rather a complex body of legislation exists which attempts to protect children from harm. Criminal Law, for example, prohibits specific types of harmful conduct (such as homicide, assault and battery and sexual offences against children).<sup>79</sup> At the same time, the Children Act 1989 and Children Act 2004 both impose a legal duty on local authorities and other organisations to safeguard and promote the welfare of children including those who are in need because they are suffering/likely to suffer significant harm. Section 31(9) of the

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<sup>76</sup> Holly Greenberry Intersex UK, Personal communication 12.06.2017.

<sup>77</sup> 2015 Committee on the Rights of Child. Concluding observations on the seventh periodic report of Switzerland. Geneva: United Nations; 2015. Report No.: CAT/C/CHE/CO/7. Retrieved from: <http://www.ohchr.org/EN/HRBodies/CRC/Pages/CRCIndex.aspx>

<sup>78</sup> World Health Organization (2016). Child Maltreatment. Retrieved from: <http://www.who.int/mediacentre/factsheets/fs150/en/>

<sup>79</sup> See, e.g. the Domestic Violence, Crimes and Victims Act 2004 s 5; Offences Against the Person Act 1861 and also the Sexual Offences Act 2003.

Children Act 1989 defines harm as the 'ill-treatment or the impairment of health or development' where 'development means physical, intellectual, emotional, social or behavioural development'; 'health means physical or mental health'; and 'ill-treatment' includes 'sexual abuse and forms of ill-treatment which are not physical'. HM Government defined child abuse and neglect to include physical abuse, emotional abuse, sexual abuse and neglect.<sup>80</sup> The *How Safe are our Children report*<sup>81</sup> defines child abuse as 'A form of maltreatment of a child. Somebody may abuse or neglect a child by inflicting harm, or by failing to act to prevent harm. Children may be abused in a family or in an institutional or community setting...' (2016: 11).

Some of the research contributors state that current practices amounted to child abuse. These perceptions may be extremely challenging to those working in the field, and to the parents who provide consent for interventions, and the highly sensitive nature of the issues is acknowledged. The key issues therefore seem to be that the impact of medical procedures may be experienced by the child as abusive, with reports of post-traumatic stress and serious long term mental health problems resulting from medical practices. Infants and young children cannot consent meaningfully to these practices, and because of this, the practices may have very damaging results.

*...the areas that we are really concerned about are inappropriate medical examinations – vaginal dilations, sensitivity testing on genitalia, photographic, the photographing of children's genitalia and exhibiting those photographs, which we've witnessed regularly at various symposiums and conferences and that's then without that person's consent. The hormonal treatment as well...live teaching events where Intersex surgeries are performed in front of audiences, medical audiences...I use this term cautiously...it's a very strong term to use, but medically raped, with regard to vaginal dilations of children. I mean horrific, I mean everything that had been perceived as a, as legally permissive, to insert a dilator into a child's newly formed vagina, in front of a room of people, it's very easy to draw illegal parallels to that, because the actual experience of that person is probably not enormously distant from the illegal...(Holly Greenberry, Intersex UK).*

*...there are common elements in the approaches to Intersex children, be they infants or older children and part of the treatment does, in my opinion, as someone who is a specialist in child mental health, is that it does amount to abuse and in some instances, torture... (Dr Jay Hayes-Light, Director, UK Intersex Association).*

The healthcare professional who contributed to the study was concerned about aspects of current practice. In particular, the practice of making children and young people engage in vaginal/neo-vaginal dilation was seen as problematic (see section 2.9). One IVSC contributor reported that psychologists are being made to enforce compliance concerning dilation. Another described the issues as follows:

*...that's not what a therapeutic experience should be, forcing compliance, you know? That just shows what a wrong road the whole, the whole body of medicine has gone*

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<sup>80</sup> Gov.UK (2015). Working Together to Safeguard Children. Retrieved from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/592101/Working\\_Together\\_to\\_Safeguard\\_Children\\_20170213.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/592101/Working_Together_to_Safeguard_Children_20170213.pdf), pp 37- 39. See also Radford, L., Corral, S., Bradley, C., Fisher, H., Bassett, C., Howat, N., & Collishaw, S. (2011). Child abuse and neglect in the UK today. pp. 20-22.

<sup>81</sup> Bentley, H., O'Hagan, O., Raff, A. and Bhatti, I (2016) How Safe are Our Children? The most comprehensive overview of child protection in the UK. NSPCC. Retrieved from: <https://www.nspcc.org.uk/globalassets/documents/research-reports/how-safe-children-2016-report.pdf>

*down, how far off-track they've gone from giving us bodily autonomy, or having a sense of agency about our bodies. Imagine the internalised sense of failure, or shame attached to that, just that, having to meet with someone regularly while they find out if you're, what your compliance level is to this. It's just, this practice, you know? I mean it's very - one would need therapy just to get over that, and then that person, at some point is meant to be able to compartmentalise that prolonged experience, and then when they do have sex, not think about that experience, that medicalised process, and then separate that out from the actual act of sex, however they might want to have it, you know? Which might not be penetrative. But so, yeah, it's - well if somebody heard this conversation we're having, they would be sitting in horror, you know? Somebody who was not experiencing this medical care (Valentino Vecchiotti, Intersex rights activist, independent academic, and author).*

Other aspects of the situation regarding IVSC medical practices also raise concern, notably the culture of secrecy surrounding the issues. The research findings show that medical professionals tend to frame the increasing claims of people who complain about medical interventions for ISVC people as 'minority' experiences or 'outliers', with the vast majority of surgical procedures and treatments being 'successful'. Unfortunately, medical professionals have yet to provide comprehensive evidence to substantiate such a claim.

The area of IVSC children's wellbeing and protection from harm is completely neglected by current child protection guidelines. The government's (2015) guidance document '*Working Together to Safeguard Children. A guide to interagency working to safeguard and promote the welfare of children*'<sup>82</sup> does not address the welfare of ICVS children. Neither is there any indication that Local Safeguarding Children's Boards, which are responsible for all children in their local area, are addressing the issue of harmful practices and ICVS children.

The *Working Together to Safeguard Children* does provide scaffolding that can potentially be used to underpin the development of measures to address the gap in provision for ICVS children. It places responsibility on NHS England to ensure that the health care system works to effectively prioritise the welfare of children. NHS England, NHS Trusts and NHS Foundation Trusts, Clinical Commissioning Groups, and Special Health Authorities all have the following duties concerning child protection: to cooperate (Children's Act 2004 section 10); to safeguard and promote welfare (Children's Act 2004 section 11), and to help with enquiries about significant harm to children (Children's Act 1989)<sup>83</sup>. Local Authorities have the responsibility for safeguarding the welfare of children and young people in their area.

#### **4.5.2 Genital Mutilation**

Female Genital Mutilation (FGM) is currently prohibited within the UK under the *Female Genital Mutilation Act 2003*. Section 1(1) provides that it is an offence whereby a person 'excises, infibulates or otherwise mutilates the whole or any part of a girl's labia majora, labia minora or clitoris.' It is designed to prohibit procedures that remove external female genital organs for cultural/non-therapeutic reasons. Section 1(2) provides exceptions to the offence, namely where a medical practitioner conducts a surgical operation necessary for the girl's mental or physical health. Section 1(5) states that culture and/or ritual are immaterial when determining whether a procedure is necessary. While this Act was not designed to prohibit intersex surgical procedures, the similarities in many surgical procedures on IVSC children raises the question of whether this Act could (and indeed should) in theory be extended to such non-therapeutic practices performed on infants.

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<sup>82</sup> Gov.UK (2015) Working Together to Safeguard Children. Retrieved from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/592101/Working\\_Together\\_to\\_Safeguard\\_Children\\_20170213.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/592101/Working_Together_to_Safeguard_Children_20170213.pdf)

<sup>83</sup> As footnote, 68, above.

Certainly, the term 'Intersex Genital Mutilation' is used by several contributors. This is because of the understanding that Female Genital Mutilation and the medically unnecessary procedures that are being carried out on infants and children without their informed consent have a common cause. One contributor, Holly Greenberry from Intersex UK, states that non-consensual surgical procedures performed on intersex children are a form of FGM<sup>84</sup>.

*FGM is outlawed and people say 'oh it's a terrible thing that some people do because of their culture', but **essentially the same thing is being done to Intersex bodies because of our culture** and people don't see that as the same issue at all and I think that they need to be careful (Annie MacDonald, representative of Trans Media Watch).*

It is cultural prejudices and traditions that provide a rationale for both sets of procedures, in the minds of those who conduct them and in the wider social support for them. Both are seen, within their specific cultural contexts, as being done for the 'good of the child', and each rely upon the regulation of sex/gender norms as a justification of the practice. The key difference is that one set of procedures, FGM, are normalised in Southern cultures which are largely Muslim, whereas the other, unnecessary IVSC medical procedures, are conducted in Western medical environments where the medics performing them deem them permissible.

*Why is FGM banned? Thank goodness it is, but why is it banned and yet some of the surgeries are performed on Intersex children – ah, they have a ready answer for that. This isn't performed in some grubby room with a rusty razor blade, you know, this is in an [unclear] operating theatre with specialists, qualified surgeons performing surgery. But the result is the same, they can destroy lives, they can also destroy a person's sex life. The number of Intersex people I have spoken to who say 'if they'd left me alone I would have been alright'. But the treatment that I have received, I have no sensitivity in my genitalia at all, which, you know, to me, actually having a sexual relationship with someone never gets off the first base and you know, I have to explain that I'm not frigid, but I can't respond, not as you would expect (Dr. Jay Hayes-Light, Director, UK Intersex Association).*

*Well that's based on a cultural norm, that's based on a social construct of what's perceived to be acceptable, which to me, and to many Human Rights defenders and activists draw direct parallels to what is legal with regards to performing female genital mutilation surgeries, because actually what's happening is there are medics who clearly state in the UK NHS, paid surgeons who clearly state they perform clitorectomies, or clitoral reduction surgeries. I mean that is horrifically abusive (Holly Greenberry, Intersex UK).*

#### **4.5.3. Torture and Inhumane Treatment**

Some contributors frame current practices as a form of torture, using international frameworks in order to do this. Specifically, the United Nations (1984) Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment<sup>85</sup> is referred to largely due to the work of the Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment in engaging with intersex concerns. This development is reflected by United Nations protocol:

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<sup>84</sup> Personal communication 12.06.2017.

<sup>85</sup> Danelius, H. (2008). Convention against Torture and Other Cruel, Inhuman Or Degrading Treatment Or Punishment. Retrieved from: [http://legal.un.org/avl/pdf/ha/catcidtp/catcidtp\\_e.pdf](http://legal.un.org/avl/pdf/ha/catcidtp/catcidtp_e.pdf)

*We have, there's been some, obviously the last couple of years, reports from the UN and the Human Rights Committee about what they describe as abuse against people who are Intersex and the special Rapporteur on Torture for the UN described what has happened to Intersex people as torture and you know, yes, it's a big word, but actually when you think about what's going on, it's a very real thing. In terms of Intersex people's rights and you know, Intersex people are a group of people that are very much and have been and I think having their rights taken away from them, you know, by performing surgeries that aren't necessary, by sterilising, by castrating people and you know, the clear abuse of someone with basic rights to health and there's many other human rights law that it would contravene, but that would take ages to go into. You know, it's just a person's basic right to their own self, you know, everybody deserves, you know, their right to be who they are and that's what's being taken away (Joe Holliday, Intersex UK).*

As is the case with the other child protection issues raised above, the notion that infants and children are being subjected to torture in UK medical establishments is highly emotive and contentious. The policy stakeholders varied in perceptions about torture, for example one civil servant said that it depends on what is done to the child, but he is reluctant to describe it as torture because it might not reflect the gravity of what torture is. There are differences in the views that groups representing intersex people, those with VSC, and others affected by VSC, have towards the idea that current practice is a form of torture. The emotional challenges that terms like 'torture' may provoke in those affected can be profound, and this needs to be taken into account by policy makers working to support the infants, children, young people and adults who have IVSC conditions, and their families. It is important to remember that the United Nations includes cruel and inhuman treatment within the 1984 Convention.

Whilst the Special Rapporteur has created a dialogue with intersex concerns in the UN context, a better starting point for the UK could be Article 3 of the European Convention on Human Rights which states that 'No one shall be subjected to torture or to inhuman or degrading treatment or punishment' and is integrated into UK law through the Human Rights Act 1998. Particularly s6(1) which states that 'It is unlawful for a public authority to act in a way which is incompatible with a Convention right.' This places particular obligations on bodies performing a public function such as the NHS. Certainly, Article 3 of the ECHR prohibits torture and other inhumane and degrading treatments or punishments.

This section of the report raises concerns about the protection of infants and children who have IVSC in the UK today. Key issues revolve around breaches of human rights, the lived experience and results of current practices, which can be felt to be abusive, mutilating and harmful, and the provision of informed consent. It seems that a proper investigation is required, with the involvement of independent stakeholders at a national level, such as Child Protection Agencies, those dealing with FGM and with torture in a domestic UK context. Such an investigation will need to include testimonies from IVSC people, and support from, and for, the intersex NGOs.

#### **4.6 The right to have children**

It is generally recognised in Article 12 of the European Convention of Human Rights that individuals have the right to procreate<sup>86</sup>. Herring notes that part of the right can be interpreted

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<sup>86</sup> Article 12 ECHR states that 'men and women of marriageable age have the right to marry and according to national laws governing the exercise of this right found a family'. However, *Paton v UK* (1981) 3 EHRR 408 ECtHR held that this does not mean individuals have apposite right to procreate and thus unfettered access to artificial insemination. See also *R v Secretary of State for the Home Office, ex p Mellor* [2000] 3 FCR 148.

as 'a right not to have one's natural ability removed by the state'<sup>87</sup>. Furthermore, the European Court of Human Rights has found in cases involving the unconsented sterilisation of cisgender<sup>88</sup> women such procedures to be a breach of Article 3 (prohibition of torture and inhuman and degrading treatment) and Article 8 (the right to private and family life). For example in *I.G. and Others* where sterilisation was found not to be a life-saving intervention and nor had the plaintiff's (who was a minor at the time of the procedure) or her parents' consent been acquired, the Court held that:

*Taking into account the nature of the intervention, its circumstances, the age of the applicant and also the fact that she belongs to a vulnerable population group . . . the Court considers that the treatment complained of attained a level of severity which justifies its qualification as degrading within the meaning of Article 3.1.*

Moreover, it continued as follows:

*the respondent State failed to comply with its positive obligation under Article 8 to secure through its legal system the rights guaranteed by that Article, by putting in place effective legal safeguards to protect the reproductive health of . . . women.*<sup>89</sup>

In 2014 a UN interagency (OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO) statement was published on eliminating forced, coercive and otherwise involuntary sterilisation in which Intersex was specifically addressed<sup>90</sup>. This statement asserts that that whilst medical procedures may sometimes be justified due to health benefits, alternatives that retain procreative capacities should be addressed<sup>91</sup>.

At present, it appears that in the UK, some babies and children born with variations of sex characteristics are still being sterilised when this is not medically necessary. Gonads that could potentially produce sperm/ova that could enable an IVSC person to have children in later life are being destroyed, often because of concerns about the somewhat increased possibility of cancer associated with some IVSC conditions<sup>92</sup>. This is highly problematic from an equalities and human rights perspective. One contributor notes that '*it is not only gonadal sperm/ova...it's about a sense of self*'<sup>93</sup>. Suggestions for alternative care pathways are provided by contributors to the research.

*...there is inherently a risk of cancer with all of us, so again appropriate healthcare and checks. But I don't think we should be fearful and within fear be completely preventative by removing tissue that is fundamentally typically healthy to that body at the point of removal. We need to be fully informed and the person needs to be monitored throughout their life and that's the specific variation they're born with. In the same way you have scans at a certain age, where concern might be raised, so at middle age, you might start having cervical smears, or you might start having breast examinations... (Holly Greenberry, Intersex UK).*

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<sup>87</sup> Herring, J. (2015). *Family Law*, Pearson: Edinburgh (see, p.404)

<sup>88</sup> The term 'cisgender' refers to people who identify with the same gender as that assigned at birth.

<sup>89</sup> Council of Europe: European Court of Human Rights (2012). *I.G. and Others v Slovakia*, App. No. 15966/04, Eur. Ct. H.R., at 144. See also Lee, R. C. (2015). Forced Sterilization and Mandatory Divorce: How a Majority of Council of Europe Member States' Laws Regarding Gender Identity Violate the Internationally and Regionally Established Human Rights of Trans\* People.

<sup>90</sup> Women, U. N. Eliminating forced, coercive and otherwise involuntary sterilization. Retrieved from: [http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1)

<sup>91</sup> See also Karkazis, K., & Rossi, W. (2010). Disorder of sex development: optimizing care. *Pediatric Reviews*; Kamar-Mattis, A. (2012) Sterilization and minors with intersex conditions in California law. *California Law Review Circuit*, 3(1):126–135.

<sup>92</sup> Though these are contested.

<sup>93</sup> Holly Greenberry, Intersex UK, personal communication 12.06.2017.

In addition, a need exists for interventions to be further developed to preserve the fertility of people who have IVSC. This includes for instance sperm preservation for people with XXY:

*...you have the fertility issue, because as you know, normally the [unclear] are virtually always infertile, however they've now recognised that many younger men in particular with have residual sperm, but these die off. So if they're diagnosed young, some sperm may be retrieved directly from the testicles and this could be frozen and kept for future use... (Representative of Klinefelters Syndrome Association).*

Overall, the research findings suggest that more careful attention to the future reproduction possibilities for children and young people with IVSC is needed. In addition, as one of the quotes included above shows (section 2.4), it seems that poor practice may be taking place regarding the reproductive capacities of some adults with IVSC, and scrutiny is needed of the situation. Such procedures may also amount to a breach of the ECHR.

#### **4.7 The Scottish situation**

The research shows that there is willingness to look at legal reform regarding IVSC in Scotland.

*Intersex people currently can't use the Gender Recognition Act in the way that other people can. I think that needs to be sorted out because Intersex people should have the same right to determine their own classification as anybody else. That is something that we can't deal with in Scotland, actually it's a UK wide issue, whether the legislation can control, I hope that that will improve (Annie MacDonald, representative of Trans Media Watch).*

In Scotland, some legal reform has taken place to support intersex and VSC people in accessing basic rights. It is not clear how far IVSC people's rights are actually covered by the Hate Crime Law and it is seen as needing amendments by some contributors<sup>94</sup>. Legal partnership rights have been addressed:

*...in 2009 through to 2010, Scotland was passing Hate Crime legislation which incorporated Intersex. The only way to get that into law was to make it part of legislation on trans hate crime, which wasn't ideal, but at least it's in there, you know, and provides explicit protection for Intersex people.....a couple of years ago, when Scotland passed its Equal Marriage legislation and made sure that Intersex would be recognised in that<sup>95</sup>, because of the issues around Intersex people not being able to change legal gender easily and so we didn't want to create a situation where people had to, where gender was part of Marriage legislation and where that created problems, and the way that the legislation is structured now, you don't have to identify a particular way in order to get married. So that basically makes it easier for Intersex people with, you know, to have whatever identity is appropriate for them and be able to use that in law when they're getting married and not have to use something that's wrong for them...(Annie MacDonald, representative of Trans Media Watch).*

The Scottish civil servants described processes leading up to legal reform as currently underway. As noted above, a consultation process across Scotland is underway (2017).

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<sup>94</sup> For example Holly Greenberry, Intersex UK, 12.06.2017.

<sup>95</sup> Intersex UK contributed to this process, personal communication with Holly Greenberry, Intersex UK, 12.06.2017.



Scottish stakeholders are reviewing the Gender Recognition Act 2004 and procedures for gender registration on birth certificates, in consultation with Intersex UK.

*...we've been talking with National Records of Scotland about registration and do Intersex people want their Intersex variation recorded as part of their birth certificate? We don't think they do, but we haven't actually engaged with Intersex people to know that. We don't know if that would be helpful for them or not, and if it would be helpful, in what instances would it be helpful? So what the Scottish Government is going to do is we're going to launch a consultation (Representative of the Equality Unit, Scottish Government).*

There was some discussion in Scotland of existing legislation being adapted to include IVSC people, including existing law regarding Female Genital Mutilation in Scotland.

#### **4.8 International changes**

The research findings show the importance of the changes in law internationally, and of emerging case law. There is some case law, including *Völling vs Regional Court Cologne* 2008 25 O 179/07, where an intersex individual successfully sued a surgeon for unnecessary medical interventions.

Anti-discrimination law and law to protect minors from unnecessary surgery has been put in place in Malta and this was discussed by both intersex contributors and some of the stakeholders.

*...probably the most active country in terms of actually making changes for Intersex people is Malta and they've brought in legislation that effectively bans the cosmetic surgeries and also introduces protections in law and in, you know, equalities laws, that protects Intersex people. Again, it's not completely perfect, but it certainly, you know, is a huge step forward...Malta, a case in point, you know, included sex characteristics as a protected characteristic within their legislation when it brought in, you know, their protection for Intersex people... (Joe Holliday, Intersex UK).*

*...and perhaps the final area we need to look at is very much the question of the legislation in Malta, which introduced restrictions on surgical interventions on Intersex children and that would be a question about whether or not we should follow suit in Scotland, in that area (Representative (1) of Scottish Government).*

The Maltese approach is supported by most of the IVSC research contributors. The parent from dsdfamilies was critical of legal approaches; she preferred other measures such as awareness raising and support for families. She saw legislation as a 'quick fix' that is unlikely to achieve real change. There is some support from elsewhere for this criticism.

*[Regarding Malta] But then people appreciate that well then it doesn't just solve everything, it just delays things, or shifts things potentially, it just means that there will be more surgery later, but then maybe in a better, hopefully, way...(Healthcare professional).*

The Maltese case shows that legislation on its own is insufficient to ensure that change is implemented. Some of the contributors discussed the need to have other processes in place to back up legislation. Legislation is seen as not working fully unless there is also an increase in public awareness. One of the contributors discussed difficulties ensuring that the Maltese law is implemented. Holly Greenberry from Intersex UK states that this is because children

are brought from Malta to the UK to undergo surgical procedures, which should (according to her) be made illegal<sup>96</sup>.

Overall, the research indicates a strong need for legal reform to ensure that medically unnecessary interventions and other harmful practices are not taking place on IVSC infants and children below the age of capacity to give informed consent. Legal changes are also greatly needed in order to prevent sex discrimination against IVSC people.

Other areas requiring legal reform were discussed by contributors, including partnership and marriage rights, sport, and education. There were some discussions about the viability of taking legal action against medics in the UK. One of the contributors mentioned the need for better healthcare for people who have suffered medical abuse, including emotional support, and for remuneration to remedy the abuse that intersex people have suffered.

## 5. Community and Alliances

### 5.1 Intersex and Variations of Sex Characteristics-related groups: Activities

NGOs and advocacy groups run by IVSC people provide a whole range of services to support the wellbeing of people who are affected by IVSC, and those around them. The group that is organised by parents, dsdfamilies, provides services to help the families of children with what they term 'Differences of Sex Development'.

The activities of the IVSC NGOs and advocacy groups include (but are not limited to): the provision of advice and information for individuals and families; awareness raising; running support groups, conference and workshops, and internet fora; media work; collaboration with medics; training including of professionals and within Universities; production of educational materials including for teachers and schools; work with LGBT organisations; international collaborations; consulting with politicians; and human rights work. The UK Intersex Association are active in promoting the rights and wellbeing of intersex people in the UK and internationally. Intersex UK undertakes public sector education and training, and lecturing. They have contributed very substantially to media coverage of the issues. To date this has included BBC 1, BBC 5 Live, BBC World News, BBC World Service, BBC Radio 4, ITV, The Sunday Times, The Guardian, The Sunday Independent, and Diva, with 74 million views of the BBC World News coverage taking place<sup>97</sup>. Intersex UK also works with UK Parliamentarians and policy stakeholders, for example contributing to Scottish policy reform<sup>98</sup>, and international human rights work with the UN and the Council of Europe. One example of activities undertaken by an advocacy and support organisation is as follows:

*We, as an organisation, we attend the RCGP [Royal College of General Practitioners] Conference for GPs and the Endocrinology Conferences. We'd love to do more of this because the GPs are so grateful to us for coming and for letting them know that a) how it affects people, but primarily that it is not uncommon. I mean I'm inclined to start off by saying 'what do you know about KSA, XXY?'...'Oh yes, very rare, mmm. One in six hundred thousand?' I mean that's not uncommon to get that response and then you say 'well its actually one in six hundred.' 'Oh gosh!' And then you talk about how many of these should they have in their practice. 'Oh!' And you know, most of them come back to us later and say 'I've had a look at my list and I've actually*

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<sup>96</sup> Personal communication, 12.06.2017.

<sup>97</sup> Holly Greenberry Intersex UK, personal communication 12.06.2017.

<sup>98</sup> Such as, Scottish Trans, see:

<http://www.scottishtrans.org/our-work/completed-work/uk-inquiry-into-trans-equality/>

*identified a couple'. We would love to attend more. Its money that's the problem and **we have a great difficulty raising money**, partly because people don't want to say they've got it, partly because it's not a cuddly sort of condition and we just seem to [unclear] if it's not a local concern, so we can't tap into local funding, we do find this very difficult (Representative of Kleinfelters Syndrome Association).*

Another example of current promising developments is that 'dsdfamilies has received grants from BBC Children in Need and Big Lottery to do consultations with children, young people and families about their care and support needs. These consultations are taking place during the autumn/winter 2017/18<sup>99</sup>'. Readers can refer to the web links in appendix 4 for more details about the work that intersex NGOs, patient advocacy groups, and other groups do.

## **5.2 Issues with resourcing and capacity**

The research findings show a marked lack of resourcing of the groups led by IVSC people in the UK. Some organisations are able to gain small amounts of funding via consultancy work, but most activity takes place on a voluntary basis. This places a severe burden on the individuals involved.

*Unfortunately we are a small organisation, but we have enormous outreach. We have to prioritise what we do with the time that we've got and you know, sometimes it is quite difficult to keep on top of...**We have a serious lack in funding** within the organisation and we have to keep a roof over our heads, so we both work full time for Intersex UK and then try to dedicate as much time as we can to other work ... I use the money that I get paid in my job to subsidise a lot of travel and a lot of expenses that Intersex UK has (Dawn Vago, Intersex UK).*

Resourcing is also problematic for organisations and individuals collaborating closely with medics. The parent-run organisation that works closely with the NHS, dsdfamilies, is able to secure some funding via grants, but a lack of financial capacity was also seen as an issue affecting the functioning of the group. There is some indication that patients who contribute to NHS consultations are not always being paid to do so.

*...often there's an emphasis placed on support groups, which is putting them under a lot of pressure in terms of supporting families, who, you know, where there's been an identification that a child's been born with a DSD, is that, I think they feel that they're not getting support from the State, from publically available sources. They're having to fill in a gap that ought not to be there (Representative (2) of Scottish Government).*

Whilst some of the contributors are extremely well regarded for their intersex human rights work, there is an issue of capacity amongst the groups working in the IVSC area. Several contributors discussed a high level of health problems affecting this population, which impact on possible actions. The very high demands on those contributors who are active mean that they are constantly overworked. Several are doing IVSC-related work on top of day jobs and/or meeting caring responsibilities. The small numbers of people who feel able to be public about their IVSC identities is a factor affecting capacity. Shame and stigmatisation also sometimes impede IVSC people from engaging in activities to address the issues that this group faces.

*...we are having capacity issues because there are, at the moment, still very few Intersex activists in the UK who are comfortable doing that kind of work [media work or training] and putting themselves potentially in the firing line and it is difficult and its*

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<sup>99</sup> Personal communication with a member of dsdfamilies, 1.10.2017.

*very, you know, there are risks for the individuals* (Annie MacDonald, representative of Trans Media Watch).

*...there's only really a handful of us at the moment. But again, that's very much down to the, really kind of a history of, you know, the shame that's been forced upon Intersex people over the years. People don't tend to, Intersex people don't tend to put themselves forward because of that...* (Joe Holliday, Intersex UK).

The issue with capacity also makes it difficult for stakeholders, including civil servants, to engage properly with this population, because many people with IVSC stay hidden. A few of the contributors discussed the need for funding for IVSC groups. As one contributor said, *'it is very hard to get funding for invisible groups'* (Valentino Vecchietti, Intersex rights activist, independent academic, and author).

### **5.3 What about alliances with LGBT groups?**

There is a trend in the UK towards placing 'Intersex' together with 'Lesbian, Gay, Bisexual, and Transgender' by people who do not themselves have variations of sex characteristics. This is seen as problematic by most contributors to the research.

*...what we observe is very common now, is that organisations are adding an 'I' on...they have no idea what they're doing and particularly with the sort of growth of sort of conversation around non-binary identities, its adding to the confusion. People are using 'I' and non-binaries [as] if they mean the same, so we made, that's in a way why it remains such a principle [of UNISON] to stand to say 'this piece of work [about intersex] is separate'...I mean I'm sure you'll have seen it a million times, organisations put out applications that they say are about LGBTI and Equality...and Intersex issues have absolutely no part of it* (Carola Towle, UNISON).

The issues that IVSC people face are very different to those that transgender and LGB people face. IVSC infants and children typically experience unnecessary medical interventions with serious, life-altering negative consequences. Some IVSC adults have to live with the permanent effects of these interventions. According to one contributor, this is the case for all IVSC adults who have had medical interventions<sup>100</sup>. These issues are simply not present for non-IVSC LGB people.

Some IVSC people are of course also transgender, and/or lesbian, gay or bisexual, and there are some important areas of shared ground (around, for example, people's rights to bodily integrity) which mean that useful alliances are possible. However, not all people with IVSC identify with the term 'intersex', or with the identity politics and rights claims approaches taken by some LGBT lobbies.

In finding ways to forge alliances that will support IVSC people, it is important to remember that differences exist within the 'LGBT' groupings as well. For example, transgender is currently pathologised and medicalised in a way that LGB identities are not.

*...it was 'LGBQ' and then you know, we argued that the 'T' should come in, and a lot of people, 'T' people, didn't want that, because they said they weren't part of that. Some people did want it, but ultimately it gave visibility, and crucially it helped with funding, you know? And the 'I' should be - just as the 'T' came before the 'Q' - the 'I' should come before the 'Q' too. And it should be 'LGBTIQ'. It shouldn't be 'LGBT+', because otherwise we would be invisible. In order for us to get funding, diversity groups need*

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<sup>100</sup> Holly Greenberry, Intersex UK, personal communication 12.06.2017.

*to know, need to see the 'I' there, so they say, 'Okay, well we've ticked the 'L' box, the 'G' box, the 'B' box, and the 'T' box - what's this 'I' box? We have to tick that box.' If there's just a '+' there, they're not going to be saying, 'Well what's this 'I' box? We're going to tick it.' So we need that visibility...* (Valentino Vecchiotti, Intersex rights activist, independent academic, and author).

The research findings raise the possibility of difficulties when 'Intersex' is placed together with 'LGBT', and policy or activist work is done by groups that are primarily LGBT-focused. Difficulties have also been highlighted in the medical literature, where LGBT activists are criticised for speaking on behalf of intersex people and their families<sup>101</sup>. The problems with attaching 'I' to 'LGBT' include the following:

- The erasure of IVSC-specific issues such as unnecessary surgery on infants and children and the termination of ICVS foetuses.
- The hijacking of funds designated for IVSC work, for example where awareness-raising projects are delivered by LGB people who are paid to do so, rather than the funds going to IVSC-led groups or professionals who can deliver work.
- Transgender intersex people having 'louder voices' within policy circles than other IVSC people.
- A political assimilation of IVSC people into broader activist claims and movements, which can override interests of the more patient-focused groups working to support VSC people, and a linked alienation of IVSC people and groups that are not LGBT.

#### **5.4 Exploring the difficulties around the ICVS and LGB groupings**

It should be remembered that IVSC people and their advocates, including parents of IVSC children, can be homophobic, transphobic and biphobic, as is the case with the rest of the population. The issue of prejudice against LGB people was evident in one of the contributor's interviews. Some IVSC people and their advocates may wish to distance themselves from the social stigma associated with LGB people. They may try to avoid linkages – in public perceptions – between IVSC and LGB people.

*I think a lot of it [discrimination against intersex people] is based on ignorance and I think some of it is also based on transphobia and homophobia, which are projected onto intersex people because people don't understand intersex* (Annie MacDonald, representative of Trans Media Watch).

The research findings also demonstrated issues with generalised fears and taboos around sexuality, as evidenced in some of the interview material regarding both parental and medical professional attitudes towards IVSC babies. It appears that some people may have a problem with considering the sexual wellbeing and development of babies and children, perhaps partly because of unconscious bias regarding the future sexual identities of these babies, or because of cultural taboos and anxieties about considering the sexuality of infants and children. Awareness raising and training is needed to openly address and deal with these issues, in a sensitive way that takes into account the feelings of parents and others.

#### **5.5 LGBT and IVSC Alliances – moving forwards**

The established nature of the LGBT 'sector' in the UK provides an opportunity for useful collaborations and alliances regarding IVSC people's wellbeing, so long as care is taken to

<sup>101</sup> Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahemed, F., D'Alborton, F., Springer, A., & Hiort, O. (2016). 'Response of the Council of Europe Human Rights Commissioner's Issue Paper on Human Rights and intersex People', *European Urology*, 70(3): 407-409. Retrieved from: <http://www.sciencedirect.com/science/article/pii/S0302283816301798>

avoid the problems outlined in section 5.3. The LGBT sector has both infrastructure and political profile; these are starkly lacking for intersex people and those with VSC. The crucial thing is that IVSC people are fully included in any work that LGBT-led organisations do, as advisors, recipients of funding, professionals delivering actions, and so on. LGBT organisations should not include the 'I' unless they are prepared and able to properly include and remunerate Intersex people. And they need to respect the fact that some IVSC people may wish to work separately from them.

*...it's very important that Intersex people and Intersex NGOs deliver Intersex work. In the same way, we wouldn't expect non-Trans people to run Trans organisations, or non-Gay people to run Gay organisations, or non-Males to run Male Fathering organisations. We take the same standpoint that the integrity and transparency and expertise comes from the appropriate Intersex people running Intersex organisations and as we grow, we anticipate, we feel very strongly about engaging and supporting new voices, regardless of their age, but new Intersex voices to join the organisation as educators and we also embrace professional advocacy from professionals (Holly Greenberry, Intersex UK).*

LGBT-led work around Intersex is often fuelled by a wish to help, in a context where provision for IVSC people is severely lacking. For example, one of the contributors, who works for an organisation primarily dealing with trans issues, reported that:

*One of the issues I feel that we have for Intersex people in the UK is that there aren't really any clearly very good support centres and [individual] at Intersex UK tells me that they constantly get people getting in touch with them, looking for support because they just, they can't find anywhere else to go. So what we're looking at trying to do, is make sure that the Emergency Support Line for LGBT people have at least a little bit of expertise, so that if Intersex people call there, they can do, you know, basic support. But they're obviously not equipped to understand complex issues and to support people over a long time, but they can deal with sort of, you know, panic and emergency situations...I think in the long term, I would like to see more Intersex only groups, or Intersex-led groups, you know, actually dominating these issues and having more direct control over it. But at the moment, it is about capacity, it's about making people aware that they can help...the main thing is to make sure they're not going to make any glaring mistakes that, you know, put people in vulnerable situations (Annie MacDonald, representative of Trans Media Watch).*

Overall, there are severe deficits in the resources that IVSC-led organisations need in order to support families and individuals who are affected by IVSC, and to undertake the range of activities required to address the social marginalisation, invisibility, and discrimination that IVSC people currently face. There is a shift taking place towards the inclusion of IVSC together with 'LGBT' taking place – it is more established in Scotland, where it is driven by the government and the Scottish Equalities Network, but is also becoming more common in other UK countries. This shift may be a positive development, but real care is needed to address the hazards that this chapter outlines. In particular, the voices, wishes, and interests of the diverse people included under the IVSC umbrella must always be prioritised, in any work that is done about them.

## **6. Equality and Human Rights**

### **6.1 A snapshot of the Equality and Diversity issues for IVSC people in the UK**

The UK has a proud history of supporting Equality and Diversity (ED) via a tranche of measures. These range from legislation through to mainstreaming mechanisms to ensure that

equalities legislation is implemented in front line service provision. There are well-recognised reasons for engaging in equalities work. These include the business case – individuals contribute more to society when they are socially included and service providers provide better services when they are diversity-aware, and the social justice case – it is fair and proper that all members of the population are able to live decent lives, free from discrimination and abuse. Whilst the gains of greater equality and human rights can be seen to outweigh the costs, measures need putting in place – legal and otherwise – to ensure that discrimination does not take place. The following quotes provide information about some of the equalities issues and ways forwards<sup>102</sup>:

*...there needs to be honesty, there needs to be an acknowledgement of reality of gender identity, you know? And the physical body, which is being acknowledged with one group: with the Trans community. It needs to be acknowledged with Intersex people, and it also needs to be clear to parents. One way that can happen, is at the port of call: at birth, so, midwives need to know; doctors need to know; doctors' surgeries need to know; hospital surgeons need to know. That has to change. Education in schools: where the notion of Intersex is brought up in Sex Education, and where it's absolutely fine, you know? Where it's made clear that it's absolutely fine, and that it's normal – that needs to happen. Just as Trans identities are brought up in Sex Education now, or LGBT identities, all these things need to be normalised through education... also being able to access information: it being made widely available, you know? If other websites linked in - so, if the BBC website, or Channel 4 website in its diversity space, linked in a link to Intersex. So, websites that support Intersex activism, or what's happening now with Intersex rights, or even to the UN site, you know? There are - or ILGA - and we could have connections, so people could easily find them, without it having to be like looking for a needle in a haystack, you know? If people could easily access information about what's currently going on, that would make a massive difference (Valentino Vecchietti, Intersex rights activist, independent academic, and author).*

*I've been speaking to those with Intersex babies and their unhappiness stems from having surgical procedures that are irreversible or have caused complications, it's not because they have, you know, different makeup from other people. That might expose them to perhaps some unfair treatment or bullying, but then I think everyone has opportunity for that at some point in their life, you know, it might be because of your hair colour, because of your size, because of your height, because of anything. So there's always something that's going to make you stand out from somebody else and I think our job is to embrace that individuality and encourage that kind of ethos in society, rather than single people out for being different and penalising them, or bullying them, or whatever it might be, you know. So **we need to change culture and society to embrace individuality and difference**, rather than pointing it out as something that separates us from other people (Representative of the Equality Unit, Scottish Government).*

*...you also need to gradually change attitudes, so that happens by making Intersex readily more visible, by saying look it's just a thing, it's nothing to be ashamed of, it's just, you know, how some people are and its sort of getting the public comfortable with it, getting people familiar with the words and around it, so that it doesn't sound like it's a strange anomaly, so that they don't assume it's your sexuality or something like that and its, you know, making it part of life and I think that we do that to a large extent through the media, also through challenging bad representation ... (Annie MacDonald, representative of Trans Media Watch).*

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<sup>102</sup> Here – and elsewhere – more space is given to ICVS people's contributions directly than might be usual in a report of this type. This is because of the need to foreground their insights.

Some promising practice concerning IVSC equalities work is apparent in Scotland, for example some specific work is being carried out regarding IVSC children's rights and wellbeing<sup>103</sup>. Scottish governmental actors work with Intersex NGOs, supported by the Scottish Equalities Network. Changes to legislation are being carefully considered, via a public consultation, which will inform a paper to the Ministers and Cabinet. Equalities work more broadly is described as follows:

*I think what is really important is that there's a really comprehensive good understanding of the issues for Intersex people in one area and then that's being streamed across Government, which is what the role of the Equality Unit is. We work on all the protected characteristics. Intersex isn't one of those, but we work on that, we develop the policy to have a really good understanding and then our role is to mainstream that across the rest of the Government, so that they have as well a developed understanding of the issues as well and then their policy can adapt and reflect what those issues are... (Representative of the Equality Unit, Scottish Government).*

However, little policy work to date is publically evident in the other UK countries, or at a UK-wide level. There appears to be a severe deficit of legal provision to protect IVSC people and to ensure their equality in the UK (see section 4). Several contributors perceive a strong need for UK governments to take leadership of the IVSC agenda, for example:

*...think it's probably (that) the government don't want to be perceived to be interfering with medical practice. But actually, you know, in terms of what's happening to Intersex people, it's got to the point where, you know, [unclear], **the government has to legislate** to protect people and yes, protect them from the medical profession, which seems like an odd thing to do, because the medical profession should be there to protect and you know, and help people. But unfortunately in this case, they're failing that. So it's time for, you know, intervention. But again, it's just trying to get everybody to really see the issues and try and work through the solutions and the medical profession itself, yes, it's a difficult one to crack because they tend to get very much set in their ways and that is information that is then passed down and down and down and nothing really ever changes and yes there has been some movement, but nowhere near enough (Joe Holliday, Intersex UK).*

*I think that **we will need to take political action, government action**, in order to deal with some of the issues in the medical community, because I don't think it's going to stop otherwise. There is a lot of hesitancy to have any kind of change within the medical service and there's been some slow progress lately, but it's very slow, you know, when you consider the damage being done. I know that the UN has been more and more active in this area and I think we need to take advantage of that moment and I think we need to push for more tolerance and then it's a question of working out the best way forward together... (Annie MacDonald, representative of Trans Media Watch).*

Sector-specific work is likely to be important in driving forwards the IVSC equalities agenda in the future. Whilst proper examination of this is beyond the scope of this report, some indicative findings were apparent in the data. One of the contributors emphasised that the need to stop unnecessary medical interventions on IVSC children and young people is linked to the need to support their educational success and potential to succeed in later life. Absences from school are known to have a negative effect on educational attainment. One contributor remarked that invasive examinations, what she describes as '*acts of medical rape*', and a lack

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<sup>103</sup> <http://www.gov.scot/Topics/People/Young-People/families/rights/child-rights-wellbeing-impact-assessment>



of emotional care and dire lack of peer support for kids also have a negative effect on educational attainment<sup>104</sup>.

*...you're stealing from their future as well as their present, if you actually pull them out of school to attend hospital, but that's tolerated. With parents who take their children on holiday during term-time are fined, it's an offence. But nobody is saying that it's an offence to pull children into hospital, because that's the medical profession's responsibility and 'we don't question that, you know'. Well some of us are questioning that (Dr Jay Hayes-Light, Director, UK Intersex Association).*

More research is needed about sector-specific reform to support IVSC people. Promising developments are, however, taking place. For example, the UK Intersex Association is providing a report to the teachers' union NASUWT to help improve educational provision in this area, and Intersex UK provides trainings and consultation. There are indications of the types of intervention required:

*... its equipping people with the tools to be able to stand up to, you know, any form of bullying, like workplace bullying, you know, online cyber bullying and you know, and bullying in schools as well... (Dawn Vago, Intersex UK).*

## **6.2 Equalities work, stigma, and the right to privacy**

In developing equalities and diversity work in the IVSC area, it is important to consider the potential ramifications of awareness raising and heightened prominence of the issues. The existence of IVSC is reported to still be largely unknown within wider society. This is seen as problematic by several contributors to the research.

*...it still seems to be quite a secretive thing to be, to be Intersex. We meet up with a lot of people who are fighting to tell their story and they don't want to step up and talk about it, which is due to being told by the doctors that it's a shameful thing and that you won't fit into society. So it's kind of bred into us, from a very early age, you know, and then our parents, you know, try to protect us, you know, so they encourage what the doctors are actually saying with regard to that, which has kind of led to a culture of it being quite shameful to be Intersex (Dawn Vago, Intersex UK).*

The contributor from the parent advocacy organisations (dsdfamilies) was extremely concerned that families and children affected by IVSC are able to keep their situation private. One of the research contributors who represented a patient advocacy remarked that a reason for the lack of discrimination that people in his community face is that the condition is hidden – he is worried that greater visibility might provoke more discrimination. This issue is found in some other equalities areas (for example issues with hidden disabilities, and with LGBT people). Holly Greenberry from Intersex UK states that *'we would never ever suggest that people disclose, but pride and openness is fine too'*<sup>105</sup>. The dynamics are also evident in the following quote:

*...the majority of XXY people, certainly in the KSA, and I would think generally, do not tell many people that they have the condition. Parents often don't tell anybody, sometimes not even close family. Some parents don't tell their children and most XXY people are very careful who they tell...we encourage, well its difficult, we now have a group of people who have decided that raising awareness is more important than their personal privacy. But, and we have parents who feel that it is important, who don't keep it hidden, but it's a slow journey...and it is difficult to encourage them because it can*

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<sup>104</sup> Holly Greenberry, Intersex UK, personal communication, 12.06.2017.

<sup>105</sup> Personal communication, 12.06.2017.

*lead to discrimination and with children, well you know what children are like, you know, and the youngsters, the youngsters are immature, well they stay immature quite often, I think, until their thirties, and because they find social acceptance difficult, they are inclined to treat anybody who tends to be a friend as a friend and sometimes share knowledge that perhaps they shouldn't and it could be used against them (Representative of Kleinfelters Syndrome Association).*

The research findings indicate overall that wider public awareness raising should take place at the same time as good practice concerning individual preferences regarding privacy. The IVSC organisation representatives describe a need for families' and children's rights to be protected, but also for IVSC to be destigmatised. For several of them, there is a link between the secrecy around variations of sex characteristics, pathologisation, and shame and stigma. Stigmatisation impacts on people's mental health and wellbeing, and according to one contributor, can also impede IVSC people's ability to organise to change society in a positive way. Destigmatisation and normalisation are required:

*...it's also about trying to make the stigma of being Intersex, you know, go away. Being able to communicate with people who are similar to you and to know that actually, you know, you're okay, **you're not disordered, you're not broken, you're perfectly normal and you know, there are others out there like you.** So yeah, regardless of whether or not you go down the route of the surgical interventions, you know, I think all support is beneficial to not just the person themselves, but also to their family... (Joe Holliday, Intersex UK).*

*I think the biggest issue that we've got is that there's not enough awareness that, you know, being Intersex is not a shameful thing. Being Intersex is just another thread of the tapestry, you know, interwoven by the human race and you know, we do belong (Dawn Vago, Intersex UK).*

Overall, there is a need for awareness-raising measures concerning sex characteristics, so that families have an easier time and issues concerning minority stress and stigma are less pronounced. At the same time, good practice concerning the rights of IVSC people and their families to have personal privacy is crucial. Those who need to respect the right to privacy can include media representatives, and service providers, for example in healthcare, early years care, and primary and secondary education. The development of policy and practice in these areas should be informed by the IVSC NGOs and support groups that are already working in this field.

### **6.3 Equality and Diversity structures and implementation mechanisms**

There appears to be a dearth of IVSC equalities implementation mechanisms in the UK. For example, the Equality and Human Rights Commission representative remarked on the absence of Equality Impact Assessments regarding medical interventions on infants and children with IVSC. It is particularly important that equality and human rights work is conducted with those working in medical settings, as the following quote indicates:

*I think the medics will think about this, the objective, they will try, oh [anxious sound] well they look at the objective [sigh], I'm trying to think, they're thinking about the physical, like what they, you know, if you, the ratings scales of what things 'should' look like and if they see something that looks very different to what it should look like, then there's the objective reason, the physical reason, they will then go the step to being (unclear) and think that as a girl living with genitalia that looks less typically like a girl's genitalia, that that must be difficult for that child, that young person and if it's a baby, it's going to be difficult for their parents, you know, as well. So they, though*

*obviously they're not psychologists, they're not thinking about them, but they are basing that on their own beliefs and values, they're basing that on having met lots of parents and children in the past and heard their stories, but they're not maybe basing it on then the next step of the wider community maybe...I don't think, **they don't go big, they don't go like 'well are we perpetuating the stigma of this by trying to normalise bodies and actually if we didn't do this, more bodies would be, you know, there's a variation', so they don't go there, so they don't go like 'human rights'*** (Healthcare professional, NHS).

In beginning to address the equalities issues of IVSC people, it is worth outlining some broader issues. There is the question of where IVSC equalities work should be located – internationally, it is mostly addressed together with LGBT work. There are good reasons for this. Policy makers need to be able to block work into 'bundles' in order to resource, formulate, and implement equalities work. Researchers need to find ways to aggregate and manage data that also do justice to the complexities of different IVSC people's interests. Numbers of IVSC people are small, which contributes to their policy erasure, especially because of the constraints of austerity. However, overall, the findings from this research show that there are difficulties with including 'Intersex' with 'LGBT' (see sections 5.3-5.5).

*I think the conflation between Intersex and Transgender needs to be better understood, particularly by policy makers and practitioners. I think there is confusion about them, like you know, in some places there's still confusion between LGBT and I and so I think some of the early steps could be to clarify what the issues are that face different communities and what the differences in those communities are in terms of discrimination and in terms of accessing rights, so that there's clear, there's clear understanding for any local authority or healthcare service or whatever to start from a meaningful place. Otherwise I think the conflation really causes confusion and it goes, it...doesn't get looked at.* (Representative, Equality and Human Rights Commission).

Whilst the research findings show a pressing need for IVSC to be made into a stand-alone protected characteristic, in order to support equality and human rights, it may be useful for policy makers to consider including IVSC together with the following groups: gender and age (children and young people). The current deficit around equalities provision for babies, children and young people affected by IVSC is particularly problematic, given the poor practices reported by research contributors. The findings from the research show that IVSC people do not generally identify with the term 'disabled'; this is because of a wish to avoid stigmatisation and pathologisation. According contributors from Intersex UK, *'Intersex people are only disabled once medically intervened'*<sup>106</sup>. However, the social model of disability, which locates the barriers that disabled people face as being within society, not the individual person, can be drawn on in developing equalities work around IVSC. Also, some of the issues concerning the need that some IVSC people have for ongoing medical support, but in a way that is patient-centred and maximises individual choice and control, are similar to those that some disabled people have. IVSC people with learning disabilities need to be well supported to make informed choices<sup>107</sup>.

Perhaps the best route forwards is to form a working group at national level to formulate strategy, with representation from the different IVSC groups, government departments (including the Department of Health) and the different equalities strands. The specific interests and needs of Black and Minority Ethnic IVSC people are invisible in current discussions and

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<sup>106</sup> Personal communication with Dawn Vago and Holly Greenberry, 12.06.2017.

<sup>107</sup> NHS Centre for Equality and Human Rights (2008). Equal Treatment: Closing the Gap Conference Report, 19 February 2008. Retrieved from: <http://www.equalityhumanrights.wales.nhs.uk/sitesplus/documents/1120/Conference%20Report%20%28FINAL%29.pdf>

this requires attention. There are some discussions about faith – the dynamics are rather different than those that can face LGBT people. One representative of an Intersex organisation and one stakeholder reported that there is support from some faith leaders (Muslim and Christian) for the cessation of unnecessary medical interventions on IVSC babies and children who are too young to consent to these. It is important to point out that intersex NGOs state that they are already leading work in this area<sup>108</sup>.

#### **6.4 Additional ideas for taking ICVS Equality and Diversity forwards in the UK**

No systematic or coordinated provision exists to support the equality and human rights of IVSC people across the UK to date. However, it is relatively straightforward to pull mechanisms and tools over from other areas of equalities work. As discussed above, this needs to be underpinned by ongoing growth and recognition of the IVSC NGO and advocacy sector, and by IVSC-specific equalities legislation.

*The problem we have is that because it's not covered in law, then there's very little we can do in terms of monitoring effective work that organisations are doing*  
(Representative of the Equality Unit, Scottish Government).

It is recognised that national UK equalities infrastructure has been diminished due to reductions in funding to the Equality and Human Rights Commission (EHRC), and that effective ways of working need to be found that involve the EHRC and other organisations. Developing equalities work in the ICVS field should refer first and foremost to the work and preferences of ICVS people. Links to resources are available in appendices 3 and 4. Some complementary ideas can be found in the book *Sexuality, Equality, and Diversity*<sup>109</sup> and the *Professionally speaking: Challenges to achieving equality for LGBT people* report<sup>110</sup>, the following key areas can be identified for development:

- Development of robust consultation mechanisms to feed into the development of policy and practice. These should include representation of the full range of IVSC NGOs and patient groups who identify with the term 'DSD'. It is suggested that a national framework group be developed to support policy development in an ongoing way and to inform (and where possible to deliver) training packages etc. IVSC people need to be properly reimbursed for their contributions, and core funding and administrative support/facilitation will be required.
- Maximising the reach of existing work being done by IVSC organisations and those supporting IVSC people, for example inviting intersex-led groups to provide paid consultancy to develop resources and deliver trainings. There some are excellent resources available already developed by IVSC NGOs, including educational and media materials. The contributions these people make should be fully acknowledged at each stage, for example in publications.
- National policy work including potentially the development of a national IVSC strategy with the support of different government departments and child protection and welfare agencies. Cross-sector efficiencies can be made by a joined-up approach.
- Development of sector-specific guidance and implementation mechanisms. Guidance and training can be bolted into existing frameworks ensuring that awareness and competencies of service providers are improved effectively across the UK. Specific

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<sup>108</sup> Personal communication with Holly Greenberry, Intersex UK, 12.06.2017.

<sup>109</sup> Richardson, D. and Monro, S. (2012) *Sexuality, Diversity, and Equality*. Basingstoke: Palgrave Macmillan

<sup>110</sup> FRA (2016) *Professionally speaking: Challenges to achieving equality for LGBT people*. Vienna: Fundamental Rights Agency.

trainings will be necessary for those in key positions such as surgeons, endocrinologists, urologists, GPs, midwives, nurses, health visitors, psychologists, psychiatrists, police dealing with hate crimes, and those working in education (for example biology and personal and sexual health education teachers).

- The use of organisational change methods in developing trainings for medics and medical policy stakeholders used to operating within the 'DSD'/pathologising and sex-binaried frameworks that have predominated within medicine for the last 60-70 years in the IVCS field.
- Policy work to address other areas in which reform to support IVSC people is important, including employment (see Appendix 4), sport, the media, and asylum and refugee services.
- Development of Equality Impact Assessments and other tools to ensure that IVSC people are able to access services as equal citizens.
- Public awareness and information campaigns, supported by public figures/champions. These need to emphasise tolerance and legal rights (if it is possible to put these in place), to counteract any potential difficulties with IVSC people becoming somewhat more visible.
- Building up robust data regarding IVSC people's concerns, the discriminations that they face, and methods to support their equality and wellbeing.

## 6.5 Human Rights and Intersex/Variations of Sex Characteristics

There is a worrying gap between Human Rights Directives internationally and current practices in the UK. Readers are invited to refer to Appendix 3 which outlines international Human Rights frameworks, in order to make their own assessment of the current situation. Claims are being made internationally, and by some UK-based intersex and CVS advocates about human rights abuses and deficits that ICVS people in the UK are currently experiencing. Some of the patient advocacy groups are also looking increasingly to human rights frameworks:

*I think that the Human Rights issue is going to be much more important for us and it's something that we, as I said, it's difficult because so many of our members are frightened of the word 'Intersex' (Representative of Klinefelters Syndrome Association).*

*The Council of Europe Articles around protecting the rights of the child are very clear and very defined around the bodily integrity of the child, the right to being treated equally and not discriminated against because of difference, the right to opportunity, equal opportunity, within education and sport, but the right to be treated equally in civil society is essential and the right not to be discriminated against or treated differently because of difference is fundamentally important and the person's right to sexual, the right that that person has to define their own sexuality and the right that that person has to define their gender...it's very difficult for a government to acknowledge that its healthcare service abuses people and it would be suggested, based on UN International Human Rights Law, whether its ratified or not, certainly doesn't defer from the fact that based on such International Human Rights Law, we commit crime (Holly Greenberry, Intersex UK).*

Some policy stakeholders also see medical interventions on children (unless necessary for basic physical functioning) as harmful practice. For example, the representative of the Equality and Human Rights Commission in England and Wales described unnecessary childhood Intersex surgeries as a form of violence against children, and as inhumane treatment and torture. Some other actors are in accordance, for instance the union UNISON supports actions against cosmetic genital surgery on children and Intersex Genital Mutilation. The Equality and Human Rights Commission, and other stakeholders, draw on a range of international

frameworks and examples in considering human rights interventions, including Council of Europe recommendations and UN Directives.

*...what we see now is a number of medically unnecessary surgeries and [unclear] before children are able to provide the medical consent and you know, they can end up in irreversible consequences for individuals and can cause, you know, great harm to individuals, both psychologically and physically and you know, the Government, and I think [unclear], I think the UN Committee on the Rights of a Child made those recommendations last year to the Government, to the UK Government, to go to bodily integrity, autonomy and self-determination and I haven't seen a fundamental response to that yet. (Representative, Equality and Human Rights Commission).*

The Scottish civil servants, who are actively engaged with the IVSC equalities and human rights agenda are currently exploring different approaches and are using frameworks such as the Convention on the Rights of the Child as part of the process of policy development.

Overall, there is a gulf between human rights claims, and the stance taken by some medics, as demonstrated above (sections 2 and 3). It appears that oppositional or adversarial approaches may not be useful in helping to develop good patient-centred care pathways and policies that support IVSC people's wellbeing, human rights and equality. Debates are ongoing in this area<sup>111</sup>. This research found that the contributor who was involved with dsdfamilies, the patient advocacy groups, and intersex rights groups, all see a pressing need to stop medically unnecessary surgical procedures on minors below the age of consent. They all support the development of more effective, and condition-specific treatment, where needed, and the establishment of better psychosocial support structures. Medical interventions including surgeries should be available for minors if they want to have these intervention, with fully informed consent and peer support, but more discussion about this is required<sup>112</sup>. The contributors identify a strong need for financial and other forms of support for people affected by IVSC who are working to support others and to effect reform. Findings from all contributors show a strong need for development of patient-centred care, properly informed by consultation with IVSC people. Consultation and partnership with IVSC people remain key to both equalities and human rights work, as the following quote demonstrates:

*...where health services and social care service are engaging communities of interest, they should go into research together, there's no reason that they can't do that also with criminal justice services or local government services, or any other. So a great more opportunity to be made by a much more creative way of engaging communities and also, you know, the opportunity for training and development ... one of the greatest areas of barriers that we face when communities are not understood and you know, working towards a really common basic level of understanding of issues, so that individuals aren't individualised and you know, they don't become a problem, that the problem is that the services squarely sits in the way in which services are delivered and it's seen that it's those that need to change or be flexible (Representative, Equality and Human Rights Commission).*

Overall, there is a need for more research that addresses the human rights issues faced by ICVS people. Medics, ICVS people, civil servants, and equality and human rights advocates could usefully work together to develop the evidence base and to formulate policies. This report raises serious concerns about current healthcare practices, legal deficits, and a lack of implementation of human rights guidelines and directives. It is hoped that the report will serve as a means of opening up discussions, potentially helping to facilitate progressive policy reform and to foster future research initiatives.

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<sup>111</sup> See, for example, <http://www.bmj.com/content/351/bmj.h5124/rapid-responses>.

<sup>112</sup> Holly Greenberry, Intersex UK, personal communication 12.06.17.



## Appendix 1: Terminology

Most of the research participants use the term 'intersex'. This umbrella term is an adjective, not a gender label or sexuality. The terms 'intersex people' or 'intersex variations' are broad enough to include most people who have variations of sex characteristics.

*Intersex is an umbrella term for people born with Variations of Sex Characteristics, which do not always fit society's perception of male or female bodies. (18)*

The term 'Variations of Sex Characteristics' is broader, and includes (for example) people with Hypospadias.

Debates exist within specific groups about terminology. For example, the majority of people with XXY chromosomes use the term 'Klinefelter Syndrome' but there is a push to introduce the term 'XXY' as this is a more generic label. XXY people may dislike both 'DSD' and 'Intersex' as descriptors, preferring the community-originated term 'Variations of Sexual Development'. This term is not used here simply because it is unwieldy to use too many terms at once, and the more commonly used 'Variations of Sex Characteristics' is similar.

The member of dsdfamilies sees the term 'Differences of Sex Development' (or 'dsd') as really useful because it brings the range of conditions together in a normalising way and highlights the 'massive spectrum of sex development'. She sees the term 'intersex' as problematic because of the linguistic linkage with 'sex', which may be unpalatable for parents of babies and young children. This opinion is in contrast to the majority of the IVSC contributors who prefer the term 'intersex'.

No IVSC/advocacy organisation supported the use of the term 'Disorders of Sex Development', which is generally used within the medical profession, because it is pathologising. Many contributors would like the medical profession to stop using the term, and they see it as a misuse of language. This is because it acts to make intersex people and those with VSC seem ill, and 'small and dependent' (Dr Jay Hayes-Light, Director, UK Intersex Association). Contributors said for example:

*I think DSD is, it's quite a pathologising term, and it's far too medicalised for what Intersex is. Intersex itself is not always, you know, a medical issue, it's just a variation of a person's sex characteristic. So by saying 'disorders' it tends to lead people to think that there must be something wrong with these people, which is not, you know, it's certainly not something that we, we advocate...(Joe Holliday, Intersex UK).*

The term 'intersex' does not appear to be widely used within the medical profession, where 'DSD' is the term of choice. There is a definitional slide taking place where 'DSD' is used – some people use it to refer to perceived 'disorders of sex development' whereas others use it to mean 'differences of sex development'. This can be seen as problematic because it is unclear and it still infers pathologisation.

Where the term 'intersex' is used by policy stakeholders, this follows their perceptions of good practice internationally. Some actors used the terms strategically, depending on which stakeholders they are working with. In one case, a civil servant stated that she understands that DSD and Intersex people have very different issues. In fact, people with variations of sex characteristics – including intersex people – are the same as those termed 'DSD' by medics – it is the terminologies and the implications of the terminologies used that are different.

The use of terminology is contested. After discussion, we decided to use the term Intersex and Variations of Sex Characteristics (IVSC) in the report as these are the most inclusive non-pathologising terms. However, it is acknowledged that this is an area of ongoing debate. For



example, Dawn Vago from Intersex UK expresses concern that the acronym IVSC could act to erase 'intersex'<sup>113</sup>. It also appears that there is a need to raise awareness about the meaning of the word 'sex' in the various terms being used; it concerns biological sex, not sexuality.

More broadly, the replacement of pathologising terms by affirmative ones has been important for a range of reforms and social movements. For example, the replacement of the term 'homosexual', which in the UK is associated with abnormality and deviance, by affirmative terms such as 'gay' and 'lesbian' was central to 1970s movements supporting the basic human rights of those who have same-sex desires<sup>114</sup>.

## Appendix 2: Methodology

In order to provide contextualised knowledge, three countries have been selected for the interviews with activists and policy makers: the UK, Switzerland, and Italy. The choice of countries supports geo-political diversity; a good range of different policies, activist agendas and patient group strategies; and differences regarding EU membership (the UK is ambivalent about the EU, Switzerland is not in the EU and Italy is a core EU member). The UK is home to several intersex activist groups and patient groups that address both social and bioethical issues. The UK has also been at the forefront of producing medical research that promotes an ethical and consensual team approach to intersex medical care; it represents a case study with high levels of social mobilisation, shifts in medical practice, yet low levels of public policy shift. Switzerland is home to one of the most active groups in Europe, *Zwischengeschlecht* (ZW) hosting DC on secondment, that operates as a mixed social-medical movement, claiming grievances for the type of care received in the past, and lobbying for new national (Swiss) and international (EU) legislation. This group has been very successful in promoting soft law shifts, yet their own analysis indicates a low level of shift in medical practice. The Swiss case study represents an example of concentrated social mobilisation (one group), low levels of medical practice modification accompanied by high policy output in terms of soft law documents. The last case study country, Italy, comprises yet another model in which we find little interaction between the patient associations and social Intersex activists, yet high interaction between patient groups and specific medical centres. This third case scenario therefore represents a hybrid situation with seemingly low levels of social activism, change in overall medical practice and legal shifts that has however embraced the growing role of the patient expert.

The project utilises a qualitative approach in order to gain an in-depth understanding of activist and policy perspectives concerning IVSC. Qualitative approaches are used to uncover and explore understandings, experiences, meanings and interpretations (Silverman, 2015)<sup>115</sup>, and are thus particularly useful when social issues require examination in-depth and where meaningful detail is sought. Within this general approach, the project is interdisciplinary in its use of concepts and tools, which it adopts from sociology, gender and sexuality studies, politics, social policy and socio-legal studies. The methods used include documentary analysis and semi-structured interviews with IVSC activists and NGO, governmental, and medical representatives. The documentary analysis involves an analysis of policy documents, best practice papers, and IVSC materials accessible on the web and in Internet discussion groups. This explores EU-wide developments in legislation, policy interventions, and also IVSC activism. The interviews carried out with IVSC activists investigate the diversity of views on gender identity, healthcare provision, activist agendas and strategies (including ways of engaging with policy makers, politicians and legislators, and interactions with health professionals), and also the range of actions that have advocated for policy or legal changes.

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<sup>113</sup> Personal communication 12.06.2017.

<sup>114</sup> See for example Richardson, D. & Monro, S. (2012). *Sexuality, Diversity, and Equality*. Basingstoke: Palgrave Macmillan.

<sup>115</sup> Silverman, D. (2015). *Interpreting Qualitative Data*. London: Sage.

The interviews with NGO, governmental, and medical representatives explore initiatives concerning IVSC, perceptions of IVSC activist and patient organisations, perceptions of national, EU, and international human rights frameworks, and other pressures experienced, for example, in relation to stakeholders and existing barriers to IVSC rights and agendas. A thematic approach, which draws out topical themes and issues for analytical comparison (Braun and Clarke, 2014)<sup>116</sup> was used to analyse the material gathered through these methods.

The research carried out for this report followed strict ethical guidelines which met all EU and national legal and ethics requirements. In particular, it adhered to the obligations set out in the Charter of Fundamental Rights of the European Union. The EU Charter is expressly helpful in underpinning the proposed research about intersex/DSD people because it demands respect for the rights of persons belonging to minorities, as explicitly mentioned in Article 2 of the Treaty on European Union and respect for the principle of non-discrimination (Article 1 of the Charter of Fundamental Rights of the European Union). The European Parliament and the European Council have made promotion of fundamental rights in the Union one of their future priorities. The proposed research will help to support the (2010) Strategy for the effective implementation of the Charter of Fundamental Rights by the European Union and in doing so supports ethical practice in research and the use of public monies. The project has received ethics approval from the University of Huddersfield; Reference: SREP/2016/080.

### **Appendix 3: Human Rights Frameworks and Directives**

Non-essential Intersex medical treatments are increasingly addressed as human rights abuses, with statements from UN agencies (Mendez 2013; UN Interagency statement 2014), the Council of Europe (2015), the Australian parliament (2013) , as well as German (2012) and Swiss (2012) national ethics committees.

Human Rights frameworks address the right to physical integrity and bodily autonomy, referring to unnecessary interventions as harmful cultural practices and inhuman treatment. Other Human Rights and legal issues include the right to life, the child's right to be consulted in medical decisions that concern them, prohibitions against torture and other cruel, inhuman and degrading treatment, protection from discrimination, access to justice and reparations, access to information, and legal recognition.

In December 2011 the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) recommended that the State party '(b) Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation' (CAT/C/DEU/CO/5).

In February 2015, the Committee on the Rights of the Child asserted for the first time that non-consensual intersex surgical procedures violate physical integrity and constitute a harmful practice during its review of Switzerland (CRC/C/CHE/CO/2-4, paras. 42 & 43).

These forms of early childhood surgery are seen to violate a child's physical and bodily integrity, their right to protection from all forms of physical or mental violence, injury or abuse (CRC art. 19) and to the highest attainable standard of health (CRC art. 24), and ultimately their survival and development (CRC art. 6).

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<sup>116</sup> Braun, V., Clarke, V., & Terry, G. (2014). Thematic analysis. In P. Rohleder & A. Lyons (Eds.), *Qualitative research in clinical and health psychology*. Basingstoke: Palgrave MacMillan.

Article 24(3) of the Convention on the Rights of the Child requires State Parties to 'take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.'

In April 2015, Malta became the first country to outlaw non-consensual medical interventions to modify sex anatomy, including that of intersex people.

**The following is an abbreviated list of recent Human Rights and Ethical body declarations.**

de María Arana, M., & Staff, H. R. C. (2005). A human rights investigation into the medical "normalization" of intersex people. *A Report of a Public Hearing By the Human Rights Commission*. Retrieved from: [http://www.isna.org/files/SFHRC\\_Intersex\\_Report.pdf](http://www.isna.org/files/SFHRC_Intersex_Report.pdf)

Veith, L. G., Wulmstorf, N., Hassel-Reusing, S. L., & Kreuzer, C. J. (2008). Shadow Report To the 6th National Report of the Federal Republic of Germany On the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). Retrieved from: [http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/AIP\\_Germany43\\_en.pdf](http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/AIP_Germany43_en.pdf)

2011 CAT/C/DEU/CO/5 (german)  
[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/C/DEU/CO/5&Lang=En](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/C/DEU/CO/5&Lang=En)

German Ethics Council (2012). *Intersexuality, Opinion*. Retrieved from: <http://www.ethikrat.org/publications/opinions/intersexuality>

NEK-CNE Swiss National Advisory Commission on Biomedical Ethics (2012). On the management of differences of sex development Opinion No. 20/2012. Ethical issues relating to "intersexuality". Retrieved from: [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf)

Méndez, J. E. (2013). Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. Retrieved from [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf)

Australian Senate Community Affairs Committee (October 2013). "Involuntary or coerced sterilisation of intersex people in Australia". Retrieved from: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)

Parliamentary Assembly (2013). Children's right to physical integrity. Retrieved from: <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=20174&lang=en>

Dan Christian Ghattas (2013). Human Rights between the Sexes. A preliminary study on the life situations of inter\* individuals. Ed. by the Heinrich-Böll-Foundation. Berlin. Retrieved from: <https://www.boell.de/en/2013/10/21/human-rights-between-sexes>

Women, U. N. Eliminating forced, coercive and otherwise involuntary sterilization. Retrieved from: [http://www.unaids.org/sites/default/files/media\\_asset/201405\\_sterilization\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf)

Gate Report (2015). Intersex Issues in the International Classification of Diseases (ICD): a revision. Retrieved from:

<https://transactivists.org/2015/10/26/intersex-issues-in-the-international-classification-of-diseases-icd/>

OHCHR (2015). Committee on the Rights of Child. Concluding observations on the seventh periodic report of Switzerland. Geneva: United Nations; 2015. Report No.: CAT/C/CHE/CO/7. Retrieved from:

<http://www.ohchr.org/EN/HRBodies/CRC/Pages/CRCIndex.aspx>

Council of Europe Commissioner for Human Rights (2015). Human rights and intersex people. Issue Paper. Retrieved from:

<https://www.coe.int/en/web/commissioner/-/europe-disregards-intersex-people-s-right-to-self-determination-and-physical-integrity>

EU Fundamental Rights Agency (FRA) (2015). The fundamental rights situation of intersex people. Retrieved from:

<http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

OHCHR. (n.d.) Fact sheet: Intersex. Retrieved from: [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf)

Committee against Torture. Concluding observations on the fifth periodic report of China. Geneva: United Nations (2016). Report No.: CAT/C/CHN/CO/5. Retrieved from: [https://digitallibrary.un.org/record/857891/files/CAT\\_C\\_CHN\\_CO\\_5-EN.pdf](https://digitallibrary.un.org/record/857891/files/CAT_C_CHN_CO_5-EN.pdf)

OHCHR Committee on the Rights of Child (2015). Concluding observations on the combined fourth to fifth periodic reports of Chile. Geneva: United Nations. Report No.: CRC/C/CHL/CO/4-5. Retrieved from:

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16403&LangID=E>

OHCHR Committee on the Rights of Persons with Disabilities (2015). Concluding observations on the initial report of Germany. Geneva: United Nations. Report No.: CRPD/C/DEU/CO/1. Retrieved from:

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>

OHCHR United Nations High Commissioner for Human Rights (2015). Opening remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons. Retrieved from:

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E>

Transgender Europe (2015). Malta Gender Identity, Gender Expression and Sex Characteristics Act. Retrieved from:

<http://tgeu.org/gender-identity-gender-expression-sex-characteristics-act-malta-2015/>

OHCHR Committee on the Rights of Child (CRC) (2016). Concluding observations on the fifth periodic report of France Geneva: United Nations. Report No.: CRC/C/FRA/CO/5. Retrieved from:

<http://www.ohchr.org/EN/HRBodies/CRC/Pages/CRCIndex.aspx>

Intersex Shadow Reports prepared by StopIGM.org/ Zwischengeschlecht.org in collaboration with International activists for the CRC, CAT, CEDAW, CRPD CCPR and UPR between 2008 and 2017, retrieved from:

<http://intersex.shadowreport.org/>

## Appendix 4: Intersex Inclusion in the UK Civil Service

The UK Civil Service is committed to becoming the UK's most inclusive employer. We have already started to progress towards this vision by delivering a comprehensive Talent Action Plan, which will embed diversity and inclusion within our Workforce Plan and reassert diversity and inclusion as one of the Civil Service's top three priorities.

The Civil Service Diversity and LGBTI Champion, Sue Owen, continues to work with other Permanent Secretary stakeholders and staff networks to ensure our workforce plan values the contribution from diverse backgrounds and fosters an environment that enables all staff to deliver the best.

In 2003, the Civil Service established a:gender, a support network for staff in government Departments/Agencies who identify with being anywhere on the gender identity minority spectrum, including those who identify as intersex. Since then, a:gender have engaged in strategic discussions on how to embed trans and intersex inclusion within policy development and have produced guidance to support staff. Amongst these things, the guidance makes clear that the Civil Service offers special paid leave to acknowledge an intersex colleague's attendance at medical appointments.

The Civil Service wants to better understand the needs of colleagues who identify as transgender, intersex or gender non-binary. As a result, the Civil Service made a public commitment to review its approach to monitoring gender identity. Our approach takes account of the findings from the 2016 Women and Equalities Select Committee's Transgender Equality inquiry that referred to a 'data gap' in understanding the needs of transgender staff. The first phase of this work includes adjusting the gender identity questions in the annual Civil Service staff survey. This will help us to understand the composition of the Civil Service workforce's diverse range of gender identities and their experiences at work. Collecting this information will help inform more focused, data driven and inclusive policies that reflect the needs of all staff. Once we have trialled this question in the staff survey, we will consult further with departments about implementing gender identity monitoring on our internal HR systems across the Civil Service.

Recently, the Civil Service has adopted a number of initiatives to demonstrate our commitment to supporting colleagues with minority gender identities and varied sex characteristics, including:

- 1) some departments introducing 'Mx' honorific titles on their internal HR staffing systems, for staff who identify with more than one gender, neither gender or identify as intersex. In 2014, the National Crime Agency identified the need to remove marital status from applications and HR systems and include a broader spectrum of options for intersex, non-binary colleagues, and those who do not wish to disclose their gender.
- 2) The Home Office has introduced dual passes for staff that wish to attend work as more than one gender.
- 3) The Civil Service Fast Stream team have also promoted transgender, intersex and non-binary issues through their monthly newsletters, held capability-building sessions for cohort leaders and have recently met with the Chief People Officer, encouraging cohort leaders to assess the impact of adopting gender-neutral language.

The UK Civil Service will be building on the progress made to date and will continue to increase our ambition for diversity and inclusion.

**Cabinet Office**  
**Government Equalities Office**

## **Appendix 5: Resources**

### **IVSC people**

The UK Intersex Association  
<http://www.ukia.co.uk/>

Intersex UK  
Info@intersexUK.org  
Twitter link: @IntersexUK

Genital Autonomy  
<https://www.genitalautonomy.org/>

Klinefelter's Syndrome Association UK  
<http://www.ksa-uk.net/>

Living with CAH  
<http://www.livingwithcah.com/>

Androgen Insensitivity Syndrome Support Group (AISSG)  
<http://www.aissg.org/>

Hypospadias UK Trust  
<http://www.hypospadiasuk.co.uk/>

OII-UK – Intersex in the UK  
<http://oiiuk.org/>

### **Organisation that aims to represent parents of children**

dsdfamilies (international)  
<http://www.dsdfamilies.org/>

### **Other resources**

Davis, G. (2015). Normalizing Intersex: The Transformative Power of Stories. *Narrative inquiry in bioethics*, 5(2), 87-89. Retrieved from:  
[http://www.nibjournal.org/news/documents/Voices\\_2016\\_OA\\_FINAL-withOLOS\\_version\\_001.pdf](http://www.nibjournal.org/news/documents/Voices_2016_OA_FINAL-withOLOS_version_001.pdf)

<http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

<http://fra.europa.eu/en/publication/2017/march-monthly-migration-focus-lgbti>

<http://onepointseven.org.uk/>

<http://www.law.leeds.ac.uk/assets/files/research/clsj/transgender-equality-response-21815.pdf>

Hughes, I. A. et al. (2006) *Consensus statement on management of intersex disorders*. Retrieved from: <http://www.aissg.org/PDFs/Chicago-Consensus-Statement-06.pdf>

Legislation.gov.uk. Equality Act 2010. Retrieved from: <http://www.legislation.gov.uk/ukpga/2010/15/contents?>

Transgender Europe (2015) Gender Identity, Gender Expression and Sex Characteristics Act (Malta, 2015). Retrieved from: <http://tgeu.org/gender-identity-gender-expression-sex-characteristics-act-malta-2015/>

Unison (n.d.)\_Unison working for intersex equality. Retrieved from: <http://www.unison.org.uk/content/uploads/2016/12/intersex-equality.pdf>

